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ALBINO YOUTH IN SOWETO

Some Features of their Adjustment

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A Dissertation submitted to the Faculty of Arts
University of the Witwatersrand, Johannesburg,
for the Degree of Master of Arts.

Johannesburg, 1977

I, Jennifer Grace Rosamund Kromberg, declare that the text of the dissertation entitled "Albino Youth in Soweto : Some Features of their Adjustment" is my own unaided work, and that all the assistance I received in its preparation consisted of technical advice detailed in the acknowledgements; that all the field-work was performed by myself and by assistants acting under my direct supervision; that all calculations have been performed and checked by me; and that the conclusions which I have reached have resulted from my own project. No part of the substance of this dissertation has been submitted in the past, or is being submitted, or is to be submitted, for a degree in any university, other than that for which I am now a candidate. The data used in this dissertation were obtained by me while on the staff of the Human Sero-Genetics Unit, School of Pathology, The South African Institute for Medical Research and University of the Witwatersrand and in the course of close post-graduate association with the School of Social Work of the University of the Witwatersrand, Johannesburg.

J.G.R. KROMBERG.

This study is dedicated to the memory of my father, David Norman Murray, who devoted a life-time to the development of social services for individuals, families and communities.

ABSTRACT

The purpose of the present study was to investigate some features of the adjustment of the young albino in Soweto, and to determine whether he differed significantly in any way compared to normally pigmented young people.

The aim of the study was threefold : firstly, to study the levels of adjustment of young albinos in comparison with a normally pigmented group of young people; secondly, to compare the attitudes of a normally pigmented group with the attitudes of albinos towards albinism; thirdly, on the basis of the data obtained from the first two aims to make suggestions for a social work service relating to albinos. Some studies on the albino had suggested that there was no discrimination against him, and others that he was psychologically less healthy than the controls and had difficulty with personal and family adjustment. The present study was an effort to explore some of these problems.

The study was set in Soweto, the local black residential area on the South Western borders of Johannesburg, where a large number of albinos were known to reside. Thirty-five albino and thirty-five control subjects, who were carefully matched according to age, sex, educational level and sub-group (Higher Primary School scholars, High School scholars and Drop-outs) were investigated. The subjects were between the ages of thirteen and twenty-two years. A schedule was constructed to test the level of adjustment of the two groups, and to determine and compare their attitudes towards albinism, and a social work service. The schedule was tested in a pilot study with fifty normally pigmented scholars of the same age and educational range as the experimental subjects. The

schedule was then modified and used in interviews with the experimental and control subjects individually. Experienced black interviewers conducted these interviews.

The schedules were scored by the writer, and Likert-type scales for adjustment and attitudes were constructed. The two groups were compared on the items on these scales by means of relevant statistical tests. Certain items on the adjustment scale required elaboration and the responses obtained on these items were analysed by two independent psychologists and further statistical data were obtained.

The results of the statistical analysis indicated that the albino and control subjects showed similar levels and patterns of adjustment. The attitudes of both groups towards albinism were very similar and reasonably positive. Specific problems were uncovered as a result of the investigation of the responses on individual items. The albinos claimed that they had problems relating to physical aspects of adjustment, to employment and to death. Both groups showed a lack of knowledge of the genetic nature of albinism.

Two albino subjects were selected for particular attention. One was a high scoring subject and the other a low scoring subject. They were discussed in the light of the writer's knowledge of their background and families, together with the data collected from their responses to the schedule. Their life adjustments appeared to support their scores on the schedule and illustrated the needs and problems of the albino.

The social worker's role was discussed, in the context of the Department of Human Genetics at the University of the Witwatersrand, Johannesburg, and with special references to the services that can be offered to the albino, and the response that should

be made to the needs indicated by the findings of the present study.

In conclusion the findings suggested that unless the problems of Soweto are so invasive that they obscure differences in adjustment between two groups so different as young albinos and non-albinos in a black community, the albino subjects were as well adjusted as the controls, within the limitations of the present exploratory study. The results also suggested that the attitudes of the two groups towards albinism were positive and this may partially account for the level of adjustment of the albinos. Certain problems, however, became evident and suggestions for further research in these areas were made. Recommendations concerned the development of services, such as genetic counselling clinics, for the albino and his family, of courses for students of social work, of programmes for the education of the community and of action-orientated research. When these plans are implemented the young albino should have a better understanding of his disorder, and an enhanced quality of life.

PREFACE

The present study was carried out by the writer as social worker, initially in the Sero-Genetics Unit, and then in the Department of Human Genetics of the School of Pathology, The South African Institute for Medical Research and the University of the Witwatersrand. Professor Trefor Jenkins, Head of the Department, provided not only an enthusiastic atmosphere for research, but continued moral support, and willingly allowed a large proportion of time, at various stages, to be devoted to the research. Dr. G.T. Nurse of the Department, placed at the writer's disposal his extensive knowledge of the people of Africa, read the manuscript and offered constructive criticism.

Without the support of the successive Directors, Professor J.F. Murray and Professor J. Metz, as well as the resources and staff of The South African Institute for Medical Research the study would not have been possible. The writer is particularly indebted to Mrs. S.M. Hébert and the Library staff for searching out articles and journals not frequently consulted by medical researchers, to Mr. M. Ulrich and Mrs. Y. Descy for most of the photographic work, to Miss J. Harding for drawing the map of Soweto, to Miss M. Louttit and Mrs. L. Herbst and their staff for typing the manuscript. Special thanks are due to Mrs. C. Marschall for so cheerfully, rapidly and efficiently typing the final draft of the dissertation.

Professor J.W. Mann of the Department of Psychology, University of the Witwatersrand, has supervised the study. Throughout he has been a continuous source of support, encouragement and wise advice. He has always been readily available and accessible to the writer and constantly motivated and stimulated the forward movement of the study. Professor F. Brümmer, of the School of Social Work, supervised

the initial stages of the study and Professor C. Muller gave freely of her expertise and original ideas during supervision consultations in the final stages of the study.

The staff of the National Institute for Personnel Research, particularly Miss S.K.P. Hall, provided invaluable advice from their vast experience with research and interviewing in the black community. Mr. Nicholas Mokopa, of that Institute, was pleasant and helpful and conducted the pilot survey interviews with interest and efficiency. Professor D. Hammond-Tooke of the Department of Social Anthropology, University of the Witwatersrand kindly lent one of his staff, Mrs. Eva Moloantoa, to carry out the interviews for the final study, and her assistance was much appreciated.

The writer is grateful to the officials of the West Rand Bantu Affairs Administration Board who provided permits for the purpose of visits and research in Soweto, and to the local Education authorities who allowed access to the schools of Soweto. Many of the headmasters were most helpful and supplied facilities for interviewing, as well as staff to assist in the selection of the subjects, and contributed to the smooth organization of the project.

Many others gave generously of their time and offered assistance and guidance during the course of the study. The writer had frequent discussions with Dr. N. Manganyi, clinical psychologist at Baragwanath Hospital, and gained valuable insights into the nature of the people of Soweto. Miss B. Lewitton and Mrs. L. Zimbler, clinical psychologists, kindly consented to score certain items in the schedules. Professor D.M. Hawkins and Dr. G.V. Kass of the Department of Applied Mathematics of the University of the Witwatersrand advised the writer concerning the use of appropriate statistical tests, and methods of presenting the statistical data.

The subjects themselves were friendly and approachable and the writer is exceedingly grateful for their ready co-operation. Assistance for the subjects, where the need arose, was provided by the staff of Ekutuleni, particularly Mrs. W. Kekana, and by several other black social workers in Soweto. Mr. G. Boswell of Alex Lipworth and Son, supplied a special cream for the albinos, using a formula compiled by Dr. Paul Keen of the National Cancer Association.

Lastly thanks are due to my children, Jacqueline and Jonathan, for their many sacrifices, which were accompanied by love, indulgence and understanding, during the course of the study.

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CHAPTER I

INTRODUCTION

1.1 Background

Helen Harris Perlman has dramatically stated that because social workers are human beings there remains burning within them a persistent small flame of hope or faith that says of the individual,

> '"But he does matter, he *is* worthwhile, his individuality *must* be recognized and respected, he *has* untapped potential, even the least of his kind". "I will", said the case-worker, "hear the voice and see the face and work toward the enhancement of the individual man".
>
> (Perlman, 1970, p. 220)

It was because the basic sentiments underlying this statement were ingrained in the upbringing, education and training of the writer that the present study became possible.

Superimposed upon these beliefs was a consuming interest in human and medical genetics, stimulated by the appointment in 1971 of the writer to the new position of social worker in the Department of Human Genetics, School of Pathology, The South African Institute for Medical Research and University of the Witwatersrand. Genetics was, and still is, a relatively new field of endeavour for the social worker. Human genetics is a rapidly developing field, in which many areas of research and service are virtually untapped. Schild (1966, p. 22) discussed the challenging opportunity for social workers in Genetics and wrote

> 'social workers, who have the professional training to help people in stressful psychosocial situations, have a rare opportunity to provide valued service, but as yet have barely tapped the surface in making their potential contribution felt'.

Finally the writer's interest in genetics and concern for the social worker's role in the field was focussed on the lives and problems of the distinct, and easily distinguishable, minority group of

people with the genetic condition of albinism, living in the black community of Soweto, in close proximity to Johannesburg.

Albinism has fascinated men for centuries. The fact that it occurs not only in animals but also in man has forced scientists to study the disorder. It became of particular interest when nineteenth century explorers discovered, amongst the black populations of Africa, people with the physical characteristics and features of the local population, but with white hair and skin. The difference was obviously striking and merited further attention. In the intervening years a variety of studies in various countries and different population groups have been carried out on the subject of albinism.

One of these studies was conducted by Keeler, who investigated the problems of the Caribe Cuna Moon-Child (the name given to the albinos among the Cuna Indians). Keeler (1953, p. 163) wrote

> 'the IQ of the moon child albinos that we studied is not in the mentally retarded range, but they do suffer psychiatrically ... The moon children led an abnormal life, restrained in many activities by their physical condition. They are largely rejected by the opposite sex. The inability to compete physically often leads them to sedentary and intellectual pursuits. Because of their weakness and rejection they develop anxieties to which they react by over-compensation or by regression'.

Do albinos lead an abnormal life? Are they restrained in many activities by their physical condition? Are they rejected? Do they show symptoms of anxiety? For the reasons that the answer to these and many other question evaded the writer and because there was a large group of albinos living in Soweto, exploratory studies, which were initially medically biased, were directed towards investigating the psychosocial aspects of albinism.

1.2 Motivation for the Present Study

The motivation for the present study arose from reading on the

subject of albinism and from the writer's experience gained in previous multidisciplinary studies of the condition.

Initially the Head of the Department of Human Genetics, Professor Trefor Jenkins, planned to employ a social worker to participate in genetic and family studies of albinism among the people of Soweto. Consequently the writer was employed and two years were spent locating families, collecting and collating information relating to the incidence and other aspects of albinism in the black population. During that time two studies were carries out on the albino group. The first was confined to an assessment of the intellectual maturity level of the young albino (Manganyi *et al.*, 1974). The second focussed on the attitudes of mothers to their albino children (Kromberg and Jenkins, in preparation). The latter investigation preceded and emphasized the need for the present study since mothers described the behavioural problems of their affected children. Maladaptive behaviour such as truancy, anti-social activity, petty crime, and unprovoked aggression was attributed to the young albino. Mothers also related instances of stigmatization of their albino children by the peer group and neighbourhood community and complained of the many physical ailments associated with the condition. These disclosures directed the writer's concern to the topic of the albino youth and the apparent psychosocial problems, as well as the possibly prejudiced community attitudes associated with this disorder.

The initial purpose of the studies was to locate cases of albinism, to compute a local incidence figure, to determine the physical condition, the needs, and the intellectual maturity level, of the albino in the black community. Gradually however the focus shifted towards a psychosocial approach which included examination of maternal attitudes. The present study was designed to ascertain

some of the personal and social circumstances of the young albino in Soweto, to investigate his level of adjustment to the society in which he lives, to explore some of the attitudes towards albinos, to identify some of the aspects of the albino's life which are amenable to social work intervention and to make suggestions with regard to services which could enhance his social functioning and quality of life.

1.3 The Aims of the Present Study

The aims of the present study were:

(1) To study the comparative level of adjustment of young albinos, specifically in the spheres of interpersonal relations, emotional life and physical well-being.

(2) To compare the attitudes of a normally pigmented control group and an albino group with regard to albinism.

(3) On the basis of the data obtained from (1) and (2) above, to make suggestions for a social work service relating to albinos.

1.4 Setting and Scope of the Present Study

The present study was set in Soweto[1], the largest black urban residential complex in South Africa. The scope of the study was limited by the numbers of albinos living in Soweto. It was planned that every albino in the age range thirteen to twenty-two years would be selected as a subject, located and approached concerning the study. In order to keep the study of the albinos themselves in perspective the scope included a review of the literature concerning albinism, a detailed description of Soweto, and a discussion on the social worker's role in genetics with particular regard to albinism.

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1. For a detailed description of Soweto see pages 31 to 47 of the present study.

1.5 Design of the Study

An appropriate programme of field-work was devised towards the accomplishment of the aims of the study. A schedule, suitable for use in a structured interview, was constructed in three parts:

(i) To outline the social profile in terms of age, sex, education, family, medical history and recreation interests.

(ii) To evaluate the adjustment level in the three specific spheres of living as stated in the aims.

(iii) To assess attitudes towards albinism and towards a social work service in Soweto.

This schedule was submitted to fifty normally pigmented subjects in a pilot study in order as far as possible to discover its strengths and eliminate weaknesses. On the results of the pilot study the schedule was improved and then administered in an interview to the albino group and a normally pigmented control group matched according to age, sex and education. A black interviewer, proficient in several Bantu languages and with experience in interviewing, assisted. The responses to the schedule were submitted to statistical analysis and to assessment by two independent clinical psychologists. The results were based on these two methods of assessment together with material from the detailed case histories of two albino subjects. The social worker's role in human genetics was discussed together with a suitable response to the findings of the present study. Recommendations were offered and conclusions drawn.

1.6 Limitations of the Present Study

It was recognized at the outset that there would be several limitations that would circumscribe both the methods used in the study and the interpretation of the results. The study was involved with

research across a cultural barrier in an area not previously investigated in South Africa. The first limitation was therefore that there would probably not be any suitable, validated, reliable instrument available for the measuring of adjustment in the local black society and that the writer would be forced to construct a schedule for this purpose. The schedule then would be based upon the writer's own concepts and preconceived notions of the problems involved. These concepts might not be those of the black community under study, and the results would thus have to be interpreted with caution.

The second limitation was that in South Africa very little research had been done on albinism, there was therefore no background available for the study. It was not known at the outset whether attitudes on the subject were too sensitive to be accurately externalized, whether they would be measurable by the means available, or whether they would be expressed with any reliability or truth.

Again little is known relating to the adjustment pattern of the average black urban youth, let alone the albino youth. The norms and life style of neither group has been described in detail, their psychosocial problems have not been analysed in any depth, nor has their adolescent turmoil, if they do have such a state, been explored. The distinction between adjustive and maladjustive behaviour is by no means clear-cut. Seldom is a young person uniformly maladjusted, everyone shows areas of competence, and satisfactory functioning, and areas of weakness in their adjustive behaviour. Adjustment is conceived differently by different disciplines. These problems together with the effect that rapid urbanization and industrialization has upon people and their adjustment constituted a third limitation which had to be taken into consideration when assessing results and drawing conclusions.

Some of the albinos and many of their families were well known to the writer and this presented another limitation. Several of the young albinos had been involved in previous research studies, whereas none of the control group were known to the writer. It was hoped that by having a black interviewer not acquainted with members of either group to assist in the research and to conduct the interviews, this limitation would be partially obviated.

1.7 Clarification of Terms

1.7.1 Albinism

Definition. Witkop (1971) uses what he calls the 'relatively unprecise definition of albinism as a hereditary defect in the metabolism of melanin[2] resulting in a decrease or absence of this pigment in skin, mucosa, hair or eyes'.

The term albino is derived from the Latin word for white, viz. albus. It was first used in about 1600 by Balthazar Tellez, a Portuguese explorer and historian, to describe the white Negroes he had seen in Africa (Pearson *et al.*, 1913).

Types of Albinism: Albinism is expressed in different forms in man. There are however two general forms of expression namely total albinism and partial albinism. This present study is concerned only with total, generalized, or oculocutaneous albinism, that is the type of albinism that shows all the features of the condition with loss of pigment in eyes, skin and hair, as shown in the photographs. (Fig. 1).

---

2. Melanin is defined as the 'dark pigment responsible for the colouration of the skin, hair and the vascular coat of the eye'. (King, 1972, p. 176).

It is very rare to find a 'complete' albino among the black peoples. Most of the albinos from the darkly pigmented races do have some pigment in their eyes, so that their eye colour is usually pale brown instead of light blue as commonly found in Caucasoid albinos in Europe. (Fig. 2).

Among those who have occulocutaneous albinism there are three types, known as tyrosinase[3] positive, tyrosinase negative and the yellow mutant. The first group have enough of the deficient enzyme to produce melanin if tyrosine is added to a cell. They usually have slightly darker colouring and frequently have small spidery pigmented patches on exposed areas of the body. The second group have none of the enzyme tyrosinase, and are very pale in colour. These two groups are complementary, so that if an albino of the tyrosinase positive type marries an albino of the tyrosinase negative type their children will have normal pigmentation. On the other hand, if individuals with the same type of albinism reproduce, their children will all be albinos.

The third group is the yellow mutant type of albinism. These albinos have skin and hair colour different from the other types of total albinism and are probably quite rare. They have a yellowish skin colouring with straw or orange coloured hair.

Symptoms: The majority of albinos suffer from eye problems such as nystagmus, photophobia and some from strabismus (squinting) and myopia (short-sightedness). Nystagmus is 'a condition in which the eyes are seen to move in a more or less rhythmical manner, from side to side, up and down, or in a rotary manner from the original

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3. Tyrosinase, an enzyme, is an essential factor in the formation of the dark pigment, melanin.



Fig. 1. Young Negro male : showing all the features of generalized albinism.



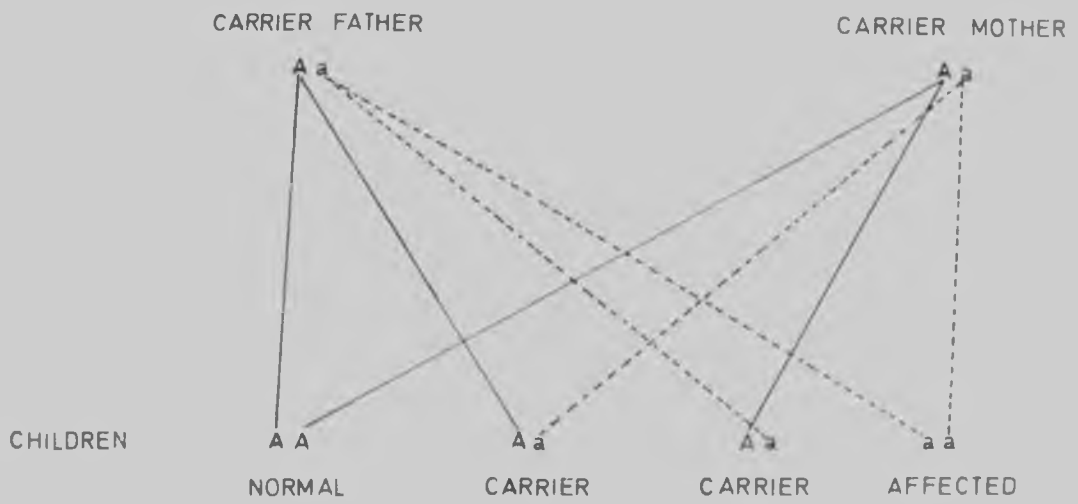
Fig. 2. Young Caucasoid male : showing all the features of generalized albinism.

point of fixation' (MacNalty, 1965, p. 985). Photophobia is 'abnormal intolerance of, or sensitiveness to light', and the term is used with reference to the eyes (MacNalty, 1965, p. 1101). It results in the continuous partial closing of the eyes to prevent the penetration of light. Skin problems are common among albinos (Oettlé, 1963), and the skin, unprotected by pigmentation, is prone to damage by the ultra-violet rays of the sun, especially at high altitudes as is the case in Johannesburg at 2000 meters. If this damage remains untreated cancer of the skin develops. The high susceptibility of albinos to skin cancer has been recognized since 1911 in South Africa (Watkins-Pitchford, 1911) and is well documented in the Transvaal (Cohen *et al.*, 1952).

Albinos have the same type and texture of hair as the race group to which they belong. However the hair colour can range from chalky white to straw-coloured to light brown. It is usually fairer in the tyrosinase negative group than it is in the tyrosinase positive albinos.

Mode of Inheritance: Oculocutaneous albinism is inherited as an autosomal recessive trait in man. This means that to produce an albino child both partners in a marriage must be carriers of the albinism gene. When two carriers marry the chances of each child being an albino is one in four, since each parent also carries a gene for normal pigmentation. The diagram shown in Fig. 3 clarifies this situation.

Albinism provides a classic example of recessive inheritance in man : the disorder only manifests itself when a double dose of the gene is present in an individual.



A - GENE FOR NORMAL PIGMENTATION

a - GENE FOR ALBINISM

Fig. 3. Diagram showing recessive inheritance.

Incidence: The incidence of albinism varies according to population group (see Table I.1). In Europe the overall frequency is about 1 in 20 000, with estimates ranging from 1 in 10 000 in Norway to 1 in 30 000 or less in southern Europe (Woolf and Dukepoo, 1969). In contrast to these figures the Cuna Indians of San Blas Province, Lower Panama, show a frequency of 1 in 200 (Keeler, 1954). The Hopi Indians of Arizona and Zuni Indians of New Mexico show similar incidence figures for albinism (Woolf, 1965).

In Africa, Barnicot (1952) carried out a study and estimated the frequency of albinism in South Western Nigeria as about 1 in 5 000. The incidence seems even higher in the Cameroons (Huizinga, 1974, personal communication) and in South Africa it is about 1 in 4 000 (Manganyi *et al.*, 1974).

TABLE 1.1. FREQUENCY OF ALBINISM IN DIFFERENT POPULATIONS

POPULATION	FREQUENCY	SOURCE
Russia	1 in 100 000	Pearson *et al.*, 1913
Italy	1 in 29 000	Pearson *et al.*, 1913
Holland	1 in 20 000	Sanders, 1938
Scotland (Glasgow)	1 in 12 000	Pearson *et al.*, 1913
N. Ireland	1 in 10 000	Fraggat, 1960
Norway	1 in 9 650	Magnus, 1922
Nigeria	1 in 5 000	Barnicot, 1952
South Africa (Soweto, Johannesburg)	1 in 4 000	Manyanyi *et al.*, 1974
Hopi Indians (Arizona)	1 in 227	Woolf, 1962

1.7.2 Nomenclature

There are problems with nomenclature in the present study. The terms used to describe the populations of South Africa are many and various. The physical anthropologist and geneticist use terms concerned primarily with the genetic constitution of a population (Jenkins, 1972) and so they designate the people of Soweto, for example, as 'Negroes'. The social scientists however consider the term 'Negro' to apply to a black person domiciled in the United States of America. To the American black person, on the other hand, the term 'Negro' is connected with slavery. It is included in a list of derogatory terms drawn up in a UNESCO report and categorically condemned by Fafunwa (Baird, 1970).

The alternative terms used to describe the population of Soweto are 'Bantu', African' or 'Black'. Wilson and Thompson (1969, p. xi) abandoned the use of the term 'Bantu' (except as a linguistic term) because 'it is disliked by those to whom it is applied'. The term 'African' is likewise unacceptable since South Africans, (as well as Rhodesians, Zambians and people from other African colonized

countries) may be of European origin, when they are frequently called 'whites', or of African origin. The word 'black' has its disadvantages, particularly in the context of the present study, since describing an Albino as a 'white black man' is obviously a contradiction in terms. Also designating people as 'black' only describes them physically and does not indicate their cultural identity. Nevertheless as Baird (1970, p. 267) states 'the word *black* is at least on a level of semantic purity with the word *white* as a description of persons, and is therefore much more acceptable than Negro'.

The procedure in the present study will therefore be to use the term 'black' to designate persons of African or Negroid origin and the term 'white' to designate persons of European or Caucasoid origin. There will be rare instances however where it will be necessary to use the term 'Negroid', to contrast with 'Caucasoid', usually in conjunction with the term albino. Terms such as 'Non-European', 'Bantu' and 'African' will be used only occasionally where these were the official terms in the specific context under discussion.

1.7.3 Adjustment

English and English (1970, p. 13) define adjustment as

> 'a condition of harmonious relation to the environment wherein one is able to obtain satisfaction for most of one's needs and to meet fairly well the demands, physical and social, put upon one'.

The only actual adjustment is relative adjustment. Complete adjustment is never attained, but is a 'theoretical end of a continuum of degrees of partial adjustment'. An adjustment level is the degree to which an individual has effected a harmonious relationship with his environment.

Adjustment involves a constant process of making changes either in oneself or in one's environment or in both, in order that things may be brought into proper and harmonious relationship, perhaps more by skill and judgement than by mere flexibility. Maladjustment is usually indicated by a failure to solve the problems of everyday living and an inability to meet the needs of the environment. Various signs and symptoms are found in conjunction with maladjustment and will be discussed in Chapter 4.

1.7.4 Attitudes

Allport's (1935, p. 798) definition is still influential:

> 'an attitude is a mental and neural state of readiness, organized through experience, exerting a directive or dynamic influence upon the individual's response to all objects and situations with which it is related'.

Triandis (1971, p. 2) provides a recent definition 'an attitude is an idea charged with emotion which predisposes a class of actions to a particular class of social situations'. This definition according to Triandis suggests that three components are involved:

(a) A cognitive component, i.e. the idea which is generally some category used by humans in thinking. Categories are inferred from consistencies in responses to discriminably different stimuli.

(b) An affective component, i.e. the emotion which changes the idea. If a person 'feels good' or 'feels bad' when he thinks about, for example, albinos, it would be said that he has a positive or negative affect towards albinos.

(c) A behavioural component, i.e. a predisposition to action. For example if a person feels good about albinos he agrees to eat from the same pot.

The three components interact, the cognitive being the minimum condition for having the attitude and becoming associated with pleasant or unpleasant events, or desirable or undesirable goals. The category then becomes charged with affect. The more pleasant the events (or the more desirable the goals) and the more frequently they occur in the presence of the cognitive component the greater is the amount of affect that becomes attached, and the more likely it is that the behavioural component will result.

1.8 Potential Usefulness of the Study

The field of genetics is receiving increasing attention from the medical profession and the general public (Jenkins, 1974). As awareness and education improves social workers in medical and other settings can expect to deal with families with inherited disorders. As Schultz (1966, p. 29) states 'the more aware social workers are of the feelings their clients have about various aspects of inherited disorders, the more helpful they can be'. Families who come to the attention of social agencies sometimes have inherited disorders. The problem is usually not entirely medical, factors such as the mode of inheritance, the threat to life and social functioning, the reactions and feelings of the family as well as outsiders, the financial strain it imposes, all affect the patient and his family. Social workers have the training and often the opportunity to be of assistance to the family with an inherited disorder.

The School of Social Work at the University of the Witwatersrand has accepted that this is a new field of exposure for the social work student and the first student was placed, for the purposes of field work practice and training, in the local Depart-

ment of Human Genetics in 1975.

It is hoped therefore that this study will make a contribution towards increasing the awareness and broadening the understanding of social workers and thereby improving their service to families with inherited disorders. The social worker has the opportunity to identify and conceptualize the psychosocial dynamics involved and to apply professional skills creatively in helping endeavours with these families, as well as to make these dynamics evident to the team dealing with the patient in the medical setting, resulting in better health care for the whole person.

This study also seeks to be useful to others who wish to do research in the black community. There is an urgent demand from social workers all over Africa (Muller, 1974) for indigenous material to be used in the teaching of social work. This study will provide a modest contribution to the supply of such material. The psychosocial functioning of the young black person has not been examined to any great extent and the study will be useful to those who wish to increase their knowledge of this section of the community.

Other disciplines have expressed interest in this study. Social anthropologists have shown interest in the findings relating to tribal folklore and belief. Educationalists have requested information from the findings that relate to the understanding, and improvement of facilities for albinos in local schools. Welfare planners, health workers, and nurses are all involved in improving the quality of life of minority groups, in this case albinos, and will find this study useful and relevant. Geneticists are interested in finding out why the gene for albinism should have such a high frequency in the local black population, when the albino would appear to be at a selective disadvantage. Similar psychosocial

studies have in the past provided them with some answers to the problem. Furthermore the approach to the technique of genetic counselling of families in which albinism occurs may be influenced by the findings of this study.

The present study may also provide useful information for the clinical psychologist, since it offers, in a limited way, an investigation of the adjustment of individuals who are physically different from their peers, makes a general assessment of their problems and offers some suggestions as to the areas in which they need help. At the same time the study provides useful information for the psychologist, social worker, and any other professional counsellor, concerning an understanding of some of the common attitudes of the community towards albinism, thereby hopefully making counselling in this situation more relevant.

Because of the above and because community organization and education have been an integral part of this study it could be useful in improving the life situation of the albino himself by promoting better understanding and acceptance of his condition by society as a whole.

1.9 Conclusion

The background, motivation, aims, setting and scope of the present study have been outlined. The design of the study has been described and the limitations discussed. A definition and description of albinism has been given. The potential usefulness of the study has been mentioned. The review of the literature on albinism in the following chapter will throw further light on the background to the present study and place it in perspective as regards world studies.

CHAPTER 2

REVIEW OF THE LITERATURE

2.1 Introduction

A comprehensive review of the literature on albinism in a study such as this is a necessity. It places the study in context, so that relationships between the earlier studies and the present one may be investigated and discussed. It also provides insight into areas in which information on the subject is lacking and to which attention might be drawn in the course of the present study.

The discussion will deal with several studies on albinism in chronological order. Only those studies which have some bearing upon the psychosocial side-effects of the condition will be examined in some detail.

2.2 Survey of the Literature

Albinism is a well-known and ancient disorder. Professor A. Sorsby (1958), Professor of Ophthalmology, Oxford, claims that Noah was an albino. Noah's birth was recorded in the book of Enoch, an extra-Biblical book to be found in the Pseudepigrapha. The statement concerning Noah's father's reaction to his birth is interesting. When his father Lamech, saw his son he was afraid and ran to his father, Methuselah, who went to the prophet Enoch for an explanation. Methuselah described the child Noah to Enoch:

> 'His colour is whiter than snow, he is redder than a rose, the hair of his head is whiter than wool, his eyes are the rays of the sun and when he opened them he illuminated the whole house'.
>
> (Sorsby 1958, p. 1587)

The story is of interest both for its description of the

characteristics of albinism in eyes, hair and skin and for its reference to the parental reaction. In a fragment from the Dead Sea Scrolls it is stated that Lamech questioned his wife's faithfulness at the time of the birth. This, as Sorsby (1958, p. 1508) writes is a 'reaction noted repeatedly through the ages in the literature on the birth of abnormal children to normal parents'. Lamech only accepted the child as his after repeated assurances by his wife of her faithfulness. The accounts of Noah's birth also state that his parents were closely related.

As early as the first century A.D. people who were probably albinos were described in the writings of Pliny and Aulus Gellius. Pliny (1942 translation) quotes Isigonus of Nicaea who related that in Albania there were men whose eyes were of a sea-green colour, and who had white hair from their earliest childhood, and that these people saw better in the night than in the day. The account of Aulus Gellius' (1948 translation) seems to refer to the same group of people. Froggatt (1960, p. 213) states that albinism was also one of the 'first inherited abnormalities to be investigated statistically on the basis of population ascertainment'. This investigation was undertaken by Roseri in 1879 in Italy.

Reports from two African countries suggest that in Africa, in the nineteenth century, albinos were killed with other deformed children at birth. David Livingstone wrote, in 1857, that while he was in Mabotsa (probably now in Botswana) he came to know the mother of an albino child. The father had refused to live with her while she kept the child, but she clung to him for many years. Eventually she killed him so that she could return to the father, and she was not punished by the authorities.

Livingstone (1857, p. 576) described the typical features of albinism in this child:

> 'The pupil of the eye was of a pink colour and the eye itself was unsteady in vision. The hair, or rather wool, was yellow and the features were those common among the Inchuenes'.

He further stated that since he had not met with any albinos in Londa (probably now a part of Angola, through which he travelled) he suspected that they were put to death there as well. He commented that there was a general absence of deformed people in Africa because of their 'due regard in infancy', and because of the natural mode of life 'as far as ventilation and food are concerned'.

The treatment of albinos was also mentioned by Livingstone. An albino woman came to him since she was most anxious to be made black. Livingstone gave her nitrate of silver, taken internally, but it did not produce its usual effect.

In 1910 Davenport and Davenport analysed many pedigrees of albino families that they had collected in the U.S.A. They concluded that albinism was inherited as a single Mendelian recessive. It appeared in twenty-five per cent of the off-spring from the marriages of carriers and did not appear in the off-spring of albinos with normally pigmented spouses.

A noteworthy monograph on albinism was produced in 1913 by Pearson, Nettleship and Usher. They included photographic evidence and indicated the incidence of the disorder in many different races and countries all over the world. Their extensive account still provides a very interesting and informative background on the subject of albinism.

Until 1942, albinism had not been as thoroughly investigated among the Negroid races as it had among the Caucasoids. In that

year Pipkin and Pipkin studied five Negro families in the United States of America. They concluded that albinism amongst the Negroes was inherited in the same way as it was in Caucasoid races. The symptoms they described were similar viz. hair colour varying from white to canary yellow to reddish; iris colour from blue to hazel to cinnamon brown; nystagmus and photophobia nearly always present and strabismus common.

The first really meaningful study in the psychosocial field was carried out by Beckham (1946) in Chicago. He posed the question 'does the albino present a psychology problem in himself?'. He proceeded to interview and psychologically examine forty-two Negro albinos. Ten years later he re-investigated the same group. A social worker visited homes with him to establish rapport and take social histories. Without the use of any scientific tool, such as an inventory, or scale, or control group, but from the social histories he deduced that 'albinos have some definitive problems' (which he does not enumerate) 'particularly those of family and personal adjustment'. Based upon these observations Beckham (1946, p. 215) stated that:

> '1. Many Negro albinos even at an early age develop a feeling of insecurity in their homes and in society generally because of the discrimination against them and the feeling of 'being different'.
>
> 2. Psychological and psychiatric treatment are often necessary to help them face their problems.
>
> 3. Albinos have acute visual problems. It is the duty of parents, teachers and other persons concerned to see that they obtain the best visual care possible'.

Beckham concluded that there was a need for better understanding of the albino at school.

Beckham's was a longitudinal study over ten years in which, as

he stated, the albinos were permitted to speak for the selves, but they were not compared with controls in any way. However I.Q.'s were measured with the Stanford Binet scale and found to be 98.5 for the males and 95 for the females which Beckham classified as average. His study indicated the need for more scientifically controlled examination of the social consequence of albinism and analysis of the psychosocial problems of the albino himself.

Beckham's research was followed in 1952 by Barnicot who presented the first study of albinism undertaken in Africa. Barnicot had observed the absence of detailed study of the African albino in the literature, and attempted to estimate the frequency of the disorder in Nigeria, while systematically gathering physical and family data. After some eight months of enquiry Barnicot estimated the frequency in South Western Nigeria to be about one in 5 000. This figure indicates a frequency which is at least twice that recorded in respect of most parts of Europe.

Barnicot admitted a weakness of his survey: 'one had the impression that albinos were not markedly handicapped with regard to occupation, but the sociological information is superficial and incomplete' (Barnicot, 1952, p. 42). He observed that although intelligence had been assessed as subnormal in some European cases it was his impression that albinos were not defective in this regard. In his small sample of twenty-one albinos, aged twenty years and over, thirteen were married, but Vallois (1950) notes that in certain tribes in the French Cameroons albinos were not allowed to marry, or did so with difficulty. In Lagos, however, Barnicot observed that there did not appear to be much discrimination against them. The mothers of the albino children seemed to regard it as a misfortune which they attributed to a

variety of causes, such as 'maternal impression or incorrect worship of their gods', nevertheless they did not appear to discriminate against their affected children. These deductions, however, were based upon observations of a small sample and they were not verified. In his closing discussion Barnicot (1952, p. 53) states that

> 'so far as social factors are concerned the attitude to albinos seems to have varied considerably in different parts of West Africa, and it is impossible to say for how long particular local customs may have prevailed'.

In 1960 Froggatt presented a paper with regard to a genetical and statistical appraisal of the condition of albinism. It was based on the data derived from a complete ascertainment in Northern Ireland Froggatt visited homes for the purpose of obtaining a full genetic and family history of each family in which there was an albino member. His study was primarily epidemiological and in his total of 138 cases he noted an excess of males over females which is supported by the data of Pearson *et al.* (1913), Sanders (1938) and Barnicot (1952). Haldane (1938) suggested that for social reasons males tend to come forward more readily than females and this might account for the excess of males over females in recorded studies. Consanguineous[1] matings are more common in albino families than in the general population and this was found to be true in the Northern Ireland data too. Although thorough in other areas Froggatt's study made no reference to psychosocial problems. The absence of any comment on problems of this nature may be ascribed to

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1. Consanguinity is a genetic relationship. Consanguineous individuals have at least one common ancestor in the preceding few generations (King, 1972), and because of this albinism is found more often in marriages which are consanguineous than in marriages where no blood relationship exists between the partners.

the fact that albinos in a fair-skinned society do not have the impact that albinos in a dark-skinned society have, due to the latter group's striking difference, from their community, in colour.

In the early 1960's Woolf started a series of studies on the Hopi Indians of Arizona who show a high incidence of albinism (1 in 227) (Woolf, 1965). Woolf became interested in the albinos of this area, not only because of their reported high frequency, but because they were said to be considered as 'good luck charms' (Woolf and Dukepoo, 1969) and have some religious significance in Hopi Indian culture. David Livingstone (1857, p. 493) too had commented, referring to albinos in Africa, that 'from accounts published by the Portuguese I was led to expect that they were held in favour as doctors by certain chiefs'. Soon after instigating investigations, however, Woolf deduced that albinos have no 'supernatural influence' and do not present as good luck charms in their villages. 'Albinos are viewed to-day as any other individual with congenital defects: they are well integrated into Hopi society' (Woolf and Grant, 1962, p. 394).

In 1969 Woolf, working with Dukepoo, concluded that younger Hopi Indians who have learned that albinism is a genetic defect may show a certain degree of discrimination against albinos. However traditional Hopis made comments which reflected only a positive attitude toward them. The fact that in Hopi society many albinos remain unmarried contradicts the attitude of complete acceptance in traditional Hopi society. 'The difficulty of being an albino in a dark-skinned population seems to have such a repressive action that suitors are rejected' (Woolf and Dukepoo, 1969, p. 36). According to Woolf and Dukepoo this point needs further investigation. The acceptance by Hopis of the Hopi heritage of albinism apparently

stops short of marriage. Any real or subconscious bias towards marrying an albino, however, does not manifest itself in the selection of a sex partner. When Woolf and Dukepoo studied the community to discover the reason for their high frequency of albinos, he found that it was not that the carrier of the gene had some genetic advantage over the non-carrier, but that the albino males were not expected to work in the fields. Instead they stayed in the villages and had plenty of time and opportunity to engage in sexual activity. In fact, according to Woolf and Dukepoo, legend has it that one old albino man never married but had as many as fifteen children.

> 'The acquisition of the albino gene by migration (or mutation) and a form of cultural selection whereby males are given a slight sexual advantage would explain the frequency of the albino gene in the Hopi population'.
>
> (Woolf and Dukepoo, 1969, p. 36)

Woolf and Dukepoo wrote further that the intriguing problem remained as to why albinos were considered so affectionately in Hopi villages.

> 'The admiration of their whiteness is clearly not an identification with white Americans; it represents instead an association of whiteness with cleanliness, goodness and purity; attributes honoured by traditional Hopis'.
>
> (Woolf and Dukepoo, 1969, p. 37)

Another study of interest was carried out by Stewart and Keeler (1965). They were able to cite only two earlier relevant articles on the psychological aspects of albinism. The first was by Seegers (1919) and involved the psychological examination of one albino child. Seegers concluded that the albino was retarded intellectually, showed emotional instability and had a tendency towards combativeness. The second study was Beckham's (1946), in which he

had not detected a significant difference in intelligence, but had suggested that albinos exhibited general feelings of insecurity. In their study Stewart and Keeler (1965) had expected to find differences in personality but not in intelligence in a group of San Blas Cuna Indians compared with a normally pigmented control group. Their subjects were twelve (six albinos and six controls) male Indians who were flown from their native Panama to Georgia where they were extensively examined medically and psychologically. A battery of intelligence tests was used including the Draw-a-person test, the Institute for Personality and Ability Testing Culture Free test of "g", part of the Wechsler Adult Intelligence Scale, the Arthur Adaptation of the International Performance Scale and a Rorschach Psychodiagnostic Test. Five clinical psychologists rated the subjects as to relative psychological health. Their conclusions showed that the albinos revealed a passive, dependent, feminine orientation, with little interest in the opposite sex. They were anxious, insecure and relied on defence mechanisms, such as intellectualization, religious pre-occupation and denial to allay anxiety. The albinos tended to deny that there was any difference between themselves and the controls, but this denial broke down under moderate stress, leading to hostile, resentful and angry responses, often resulting in withdrawal. 'In general the albino shows a markedly less accurate perception of reality' (Stewart and Keeler, 1965, p. 323). They were rated by the five judges as being psychologically less healthy than the controls, although tests of significance were not computed. The albino was also immature emotionally and Stewart and Keeler suggested that this might be due to early parental overprotection or to the inheritance of a poorer basic personality, or to an interaction of both factors. Stewart

and Keeler, however, agreed with Beckham that there was no significant difference in intelligence. They suggested that their results needed further confirmation with a larger sample and in a less stressful situation.

Freire-Maia and Cavalli (1972) found a Brazilian island which had a small population of 400 people, amongst whom there were eighteen albinos, giving a very high incidence of about one albino in twenty-two people on the island. They carried out medical and genetic studies on the group. No comment was made on the psychosocial status of the albinos or the level of acceptance in the society, but their results are preliminary.

In an effort to investigate the intellectual maturity and body image boundary characteristics of albinos Manganyi *et al.* (1974) carried out a study of albinos in the black population of Johannesburg. Twenty-eight albino subjects were compared with a carefully matched normally pigmented control group. The findings showed that the albinos performed slightly better than the controls on the Draw-a-person tests used, and it was concluded that albinos have intellectual status well within the normal range. The albinos however showed a slightly less diffuse body image boundary differentiation than the control group.

This study was followed by a further study (Kromberg and Jenkins, in preparation) on the maternal attitudes of mothers of albinos in the black community in Johannesburg. Fifty-six mothers were interviewed, with a schedule constructed to obtain information on their attitudes to having albino children. The preliminary conclusions of this study support in part Stewart and Keeler's findings that mothers tend to overprotect their albino offspring. The results showed that mothers differentiated between the albino

and his normal siblings, expecting more from the albino and giving him more opportunities for education and advancement. Stewart and Keeler's (1965) comments on interest in the opposite sex and Vallois' (1950) comments on marriage were partly substantiated and there was some reluctance by the mothers to permit marriage of their albino offspring, particularly the females. This latter conclusion however needs further study using a matched control group.

2.3 Summary and Conclusion

It appears that several of the psychosocial features of albinism have been studied in some detail. The question of intelligence has been clarified, the evidence indicates that the albino does not appear to suffer from any form of mental retardation and his intelligence falls within the normal range.

Beckham (1946) made the first contribution to the psychosocial nature of the disorder when he concluded that albinos suffer from feelings of insecurity and may need psychological counselling to help them adjust to their problems. He indicated the need for further research into albinism and the role of the albino at home and at school.

Barnicot (1952) similarly showed the need for further sociological studies. He observed that albinos were not markedly handicapped in the employment field but that this and other social factors were insufficiently researched. He highlighted the problem of marriage and the fact that some albinos were not married at an age when most of the general population were married. Vallois (1950) confirmed this finding in the French Cameroons.

Livingstone (1857) commented on an extreme parental reaction which resulted in death to the affected child. Individual, family

and societal attitudes to albinism in Africa have not however been extensively examined. Barnicot (1952) briefly mencioned attitudes to albinos. He observed that the attitude to albinos varied considerably in different parts of West Africa. He could not say how long particular local customs, which appeared to be non-discriminatory, might have prevailed.

There are no data to show whether albinos are treated differently from normally pigmented individuals in a number of societies throughout the world. Woolf (1962, 1965) commented on this problem in his studies on the Hopi Indians and although he claimed that the albinos were well integrated into society, it would appear that the majority, nevertheless, remained unmarried. Woolf could find no reason for such behaviour and suggested the need for further study in this area. Stewart and Keeler's (1965) findings confirmed Woolf's conclusion that albinos showed little interest in the opposite sex. Stewart and Keeler found that the six albinos they studied were anxious, insecure and emotionally immature. They also found that albinos employed a certain amount of denial as a common defence mechanism. They suggested however that these results be confirmed with a larger sample.

Two of the aspects of albinism have been investigated in Johannesburg, viz. the problem of the albino's intellect, and that of maternal attitudes to albinism. It is proposed that the scope of the first two stated aims of the present study[2] should include research on the following problems suggested by earlier studies:

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2. See page 4 of the present study.

(i) The interpersonal aspects of the albino's adjustment to society, dealing with marital, employment and other problems, including a study of the attitudes of society to the albino, which was briefly commented on by Vallois (1950) and Barnicot (1952) but not studied in any depth;

(ii) the emotional aspects of individual adjustment, dealing with the feelings of insecurity and anxiety previously studied on a small scale in the Hopi Indians by Stewart and Keeler (1965);

(iii) the physical aspects of albinism as they influence adjustment to self, dealing with the problem of what the albino believes the extent of his physical problems are, an aspect of the situation which has not received the attention of previous researchers.

The study of the literature reveals that there are aspects of albinism which have not been investigated in sufficient detail and suggestions have been made for further research. The present study will try to fill some of these gaps and to contribute new information on some of the psychosocial aspects of albinism. It will explore some features of the adjustment of the young albino in Soweto, Johannesburg.

CHAPTER 3

SETTING OF THE FIELD-WORK : SOWETO

3.1 Introduction

Arising from the survey of the literature, from the paucity of information on albinos in black communities and from the writer's previous experience, it was decided that the study should concern the problems of the albino, in the local black community, in the emotional, social and physical aspects of his life.

Although the writer knew a few families of European origin and others of mixed descent in which there were albinos, the study was confined to the black population group of Soweto, Johannesburg. It seemed that the albinos in this group, differing so strikingly in appearance from the normally pigmented members of their society, would have relatively more problems in life than would their counterparts in lighter-skinned population groups, who cannot be so readily differentiated from their community.

The setting chosen for this study was Soweto, a black urban complex of townships close to Johannesburg. It is one of the largest concentrations of black people living in a circumscribed area in Africa. It is readily accessible from Johannesburg and can be reached from there by road within thirty minutes. Previous studies in the area suggested a provisional frequency figure for albinism of 1 in 4 000 (Manganyi *et al.*, 1974). This relatively high frequency meant that one could expect to find, in Soweto, sufficient albinos to make the study of a limited age group worthwhile.

In order to understand the albino within this community and to facilitate a more accurate interpretation of the findings it

is necessary here to make a brief study of Soweto, in terms of its background, people, needs and facilities.

3.2 Historical Background

In the early years of this century the black population of Johannesburg was made up of males who came to work in the city on short-term contracts. By 1905 they had begun to bring their families to live near their place of employment, and the first township to be built in the area to the South West of Johannesburg was Pimville, in the same year. The Non-European Affairs Department of the Johannesburg City Council was established in 1927, and one of its functions was the control of African housing.

During the period spanned by the Second World War, the black population of Johannesburg increased very rapidly. The Non-European Affairs Department housing division could not cope with the escalating needs, since the emphasis at the time was on war-related problems and plans to deal with other social problems were largely shelved. Eleven 'shanty-towns' mushroomed to accommodate the overflow of people. Shacks were built of tin, cardboard, corrugated iron, hessian, mud and bits of wood and wire, and slum conditions consequently prevailed. Shortly after the war ended, however, work started on the improvement of these areas and the provision of housing and essential services such as running water and sanitation. The major part of this work has taken place since 1956, and there are now no slum areas as such left in Soweto, apart from a small derelict section of Pimville. The name Soweto was introduced in 1963 and was derived from the first two letters of each of the words 'South Western Townships'. The area covered is about ninety square kilometers.

Apart from the twenty-six townships which made up Soweto and were administered by the Johannesburg City Council there were two adjoining townships established in terms of the Bantu Resettlement Act of 1954. Blacks had owned land in suburban areas to the West and North-East of Johannesburg since the early years of this century, and in 1955 the Bantu Resettlement Board began the removal of people to the Board-controlled townships of Meadowlands and Diepkloof (see Fig. 4). These areas are unofficially included in the term Soweto and in the figures given in this Chapter. People from these areas participated in the present study.

In July 1973 the administration of the twenty-six Johannesburg City Council-controlled townships, together with Meadowlands and Diepkloof, was transferred to the newly formed West Rand Bantu Affairs Administration Board (W.R.B.A.A.B.). The Board also took over the administration of the black residential area of Dobsonville, attached to the nearby town of Roodepoort and adjacent to Soweto, but this suburb is not included in the present study. The development of this Board meant that the affairs of the whole area would be in the hands of one government-controlled body.

Soweto, then, in the context of the present study, is the black residential area South West of Johannesburg, administered by the W.R.B.A.A.B. and including Meadowlands and Diepkloof, but excluding Dobsonville.

3.3 The Population

Official estimates for the population of Soweto vary. The figures from the last National Census (1970) were 587 970, compared with the total figure for all races in Johannesburg of 1 407 963. The superintendents of each of the townships in Soweto make regular



Fig. 4. Map showing Soweto : its area, railways, main roads and suburbs, including Meadowlands and Diepkloof (based on the map drawn by the Town Planning Branch, Johannesburg).

reports, and in June 1974 they gave the figure as 610 450 for Soweto. This figure is an under-estimate, however, as many people in Soweto fail to register the births of their children and fail to include the names of all the people in their houses on their housing permits, from which the superintendents derive their information. It was estimated that the under-enumeration during the government Census of 1960 amounted to about 17 per cent (Hellman, 1971). Unofficial estimates for Soweto range from 800 000 to 1 million (Sunday Times, 20/10/74)[1]. This figure including the many 'illegal' residents, who are people who do not qualify to be in Johannesburg in terms of the Bantu (Urban) Areas Consolidation Act.

The population of Soweto is young and in 1965 an age distribution table showed that 54 per cent of the population was aged nineteen years and under (Non-European Affairs Department research reports). Recent figures are not available, but there is no reason to believe that the present situation is very different.

3.4 Families in Soweto

The basic social unit in Soweto is the family and there are over 110 757 families living there (W.R.B.A.A.B. Annual Report, 31/3/76). The majority of these families have their own houses, but there are 15 800 living with other families as lodgers or sub-tenants.

The urban family is not necessarily the extended family of the rural society. In the rural areas the black household consists of a variable biological unit together with dependent relatives. But in the cities the family generally consists of the members of the

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1. Several attempts to obtain a more reliable, up-dated and official figure for the total population of Soweto have failed to provide a more adequate statistic than the one given here.

nuclear family of the household head. The mean size of the family unit in 1969 was 5.24 and of the household size 5.85 (Hellman, 1971). Pauw (1963, p. 149) carried out a study on 109 families in East London's black townships and found that while 'the elementary family is the basic type, it shows a strong tendency on the one hand to lose the father at a relatively early stage and on the other hand to develop a multigeneration span'. Nearly 50 per cent of the East London families had female heads, whereas the percentage in Soweto in 1976 was 24.29 per cent or 25 277 families altogether (W.R.B.A.A.R. Annual Report, 31/3/76). Among the Soweto families who lived as lodgers, however, almost 40 per cent had female heads. The crude birth-rate was 37.5 per 1000 in 1963, but the birth-rate appears to be dropping, due to the awareness of the women that there is a better chance in life if the number of children is limited, and to the availability of advice on family planning at local clinics (Hellman, 1973).

Behaviour in the Soweto family is generally still based on the strong patriarchal tradition of the tribal society and on the principles of male dominance and female subservience. Where the female becomes a wage-earner and assumes increasing responsibility for the education expenses, budgeting and household management the stability of the family is threatened. This change in the traditional roles in the family leads to marital discord, infidelity and a rising incidence of divorce (Hellman, 1971), as well as desertion and illegitimacy, and associated problems in the sphere of parent-child relationships (Manganyi, 1973).

3.5 Housing

There were approximately 95 662 dwelling units in Soweto in 1975

(W.R.B.A.A.B. Annual Report, 30/3/76). They are built in a variety of styles ranging from single detached houses to 'train' houses (several small houses attached to each other in a straight row). The standard house has four small rooms (see Fig. 5, page 40) and the average rent is R10-60[2] per month. There is a system of rebates for those tenants, generally pensioners, who earn less than R 30-00 per month. Each house has its plot of ground which may or may not be cultivated depending on the tenants' interests. Although some houses have in the past been bought by the residents, there are restrictions on home ownership and there is also a ban on the purchase of land in Soweto.

The older townships of Soweto house people of mixed tribal origin. In 1955 however, ethnic grouping was introduced and since then, if a house is vacated, it is rented only to a person of the ethnic group for whom the area has been zoned. In 1971 there were ten predominantly Nguni areas, six predominantly Sotho, one Sotho/Nguni, one Venda/Shangaan/Tsonga and eight mixed townships in the Council controlled areas.

Hostel accommodation is provided for single men and there are nine such hostels in the area catering for 43 263 men (W.R.B.A.A.B. Quarterly Report, June 1976). There is a waiting list for those requiring accommodation in these hostels and according to the June 1976 W.R.B.A.A.B. Housing Report there were 9 580 names on this list.

There is also a long waiting list for housing and the present estimate is that there are 10 311 duly qualified family heads

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2. In November 1976 the rate of exchange for the Rand was $ 1.15 (U.S. dollars).

waiting for houses. It is estimated that 2 000 houses are needed every year to accommodate Soweto's own newly married population alone (Hellman, 1973).

Essential services such as running water, sanitation, refuse removal and postal deliveries are provided for every house. Approximately 20 per cent of the houses are electrified and in March 1973 the Johannesburg City Council approved a plan to electrify the whole Soweto complex over a period of eight years. A start was made in November 1973 to install high-mast street lighting, and to-date almost half Soweto has been provided with this service (see Fig. 6, page 40).

3.6 Education

In 1973 there were 145 schools in Soweto catering for 115 000 children (The Star, 9 January 1973). In 1976 within the expanded boundaries of the W.R.B.A.A.B. area there were 288 schools catering for 172 000 children (W.R.B.A.A.B. Annual Report, 31/3/76).

The Minister of Bantu Education said in the Assembly on 23 February 1973 that about 76 per cent of black children in South Africa in the age group 7 to 15 years were enrolled at schools in 1972 (Horrell and Horner, 1974). In Soweto itself there are very few children who never go to school, but close on 70 per cent never get beyond the first four years of primary schooling (Hellman, 1971). Many schools still operate on the double session basis, whereby one teacher takes two different classes and the children involved, particularly the first two grades, only get 2½ hours of teaching per day. In the whole of South Africa the number of black children receiving this type of education was 72 per cent in grade I and 73 per cent in grade II in 1973 (Horrell *et al.*, 1975).

One of the biggest problems in the black educational system is the high drop-out rate. The largest number of drop-outs occur after the first year of schooling. Various factors, including economic, community (such as the attraction of gangs), health, behavioural and learning problems play a part in producing the high drop-out rate. Family factors are also important since it appears that many black parents have lost control of their children (Hartshorne, 1976). Then also, the school may be inaccessible, (children sometimes having to walk eight to ten kilometers to school and back again) and may have minimal holding power. All these problems contribute to raise the drop-out rate amongst the youth of Soweto. Nevertheless the Education Department is planning to make education for blacks compulsory within five years, and in 1977 will request every black parent of a Grade I child to sign an undertaking to keep their child in school for four years. In terms of a widely-used UNESCO definition, four years is the minimum schooling required for literacy (Hartshorne, 1976), so that children dropping out of school during the first four years may be classified as functionally illiterate.

In 1976 there were 177 lower primary schools (see Fig. 7, page 40), 100 higher primary, nineteen lower and higher primary together, twenty-eight junior secondary schools, ten senior secondary schools and four technical schools in Soweto. There is keen competition for places in post-primary schools. University education is available in the tribal homeland of origin. Provision also exists with special permission from the Minister of Education, for a student to attend a white University if the course of his choice is not available at a black University. In 1974 there were 309 black students enrolled at white Universities, the majority



Fig. 5. Some semi-detached houses in Soweto.



Fig. 6. A view of Soweto showing housing, high mast street lighting and sports fields.



Fig. 7. A lower primary school in Soweto with a group of scholars, including an albino, and two drop-outs.

(250) being students in the Medical School attached to Natal University. The total number of black students at Universities in South Africa for that year was 7 845, which included 3 995 enrolled with the University of South Africa for correspondence courses only (Horrell *et al.*, 1975).

No information is available yet from the 1970 census on the educational standard reached in Soweto. Rädel *et al.* (1963) give the following figures for household heads in Soweto: 0.1 per cent had Matriculation certificates, 4.1 per cent had Junior certificates, 19 per cent had passed Std. VI, 35 per cent had only some schooling and 39 per cent had no schooling at all.

3.7 Income

The University of South Africa's Bureau of Market Research estimated in 1975 that the minimum subsistence level for a five-person black family was R111-00 per month. According to the W.P.B.A.A.B. Annual Report (31/3/76) the average monthly wage for male workers ranged from R51-67 (domestic workers) to R102-56 (workers in industry), and for female workers ranged from R40-13 (domestic workers) to R71-90 (wholesale and retail trade). Almost half the wives in Soweto, however, are gainfully employed and they play an important part in supplementing the family income.

In 1973 the Bureau of Market Research found that 82 per cent of Johannesburg's black households with male heads had incomes above the minimum subsistance level for the area, and one can assume the present state of affairs in Soweto is not very different.

3.8 Employment

Adults living in Soweto must qualify for a permit to work in the

Johannesburg area and are required by law to register at a central City office as workseekers.

Employment opportunities for blacks are being diversified. An analysis of the types of employment of male workers in Johannesburg showed that those employed in semi-skilled work increased from 34.9 per cent in 1966-67 to 44 per cent in 1968-69 and those in skilled work from 8.2 per cent to 12.3 per cent; at the same time the number of unskilled workers decreased from 66.8 per cent to 42.8 per cent of the total (Hellman, 1971). The South African economy is expanding and the shortage of white labour is producing increased opportunities for blacks to become artisans and white-collar workers.

3.9 Facilities

3.9.1 Medical

Facilities for medical treatment are available at ten clinics in Soweto. The charge is 50c per patient for two visits, and this sum includes treatment. In-patient treatment can be obtained at Baragwanath Hospital (which has over 3 000 beds) on the southern boundary of Soweto (see Fig. 4). Charges for hospitalization are made on a sliding scale ranging from 50c to R7-50 per day according to income, and the charge per out-patient treatment at the hospital is 50c for two visits. For those Soweto residents who wish to be private fee-paying patients, there are fourteen medical practitioners in private practice in the area. There are also many diviners and herbalists[3]

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3 A diviner is a 'specialist who diagnoses the "real" cause of the disease' (Hoernlé, 1937, p. 230); in some Bantu-speaking tribes diagnosis is made by divination with bones, in others supernatural influences and the spirits of the ancestors play a large part. A herbalist is a specialist who claims to 'have a wide knowledge of the properties of plants (and animals) and to be able to compound ingredients from these sources for the cure of disease and the protection of man, beast and home, and also for securing success in manifold activities and undertakings' (Hoernle, 1937, p. 228).

available for those who prefer to turn to traditional methods of treatment for their misfortunes and disease. It has been suggested that possibly a majority of people in Soweto use a combination of traditional and Western medical services (Manganyi, 1974).

3.9.2 Transport

Soweto is provided with transport in the form of a central train service, buses and taxis. A number of people run private motor vehicles. About 197 000 people commute by train and 147 000 travel by bus to work in the city of Johannesburg daily (Report of the South African Railways. October, 1975).

3.9.3 Recreation

There are facilities for a variety of recreational pursuits including sports, such as soccer, swimming, tennis, athletics, golf and bowling. Soccer is one of the most popular pastimes, and there are 115 playing fields available, with 1 000 amateur and fifteen professional teams participating in the sport. Sports clubs and associations abound and there are also separate clubs organized for men, women and children, for recreational, cultural, welfare, service and educational purposes. Recreation centres are run by church groups and the W.R.B.A.A.B. For cultural stimulation there are drama groups, music festivals, choral activities, and an active art centre. Two privately-owned cinemas provide entertainment and six W.R.B.A.A.B. halls run plays with local actors or popular films twice a week, at the maximum cost of 50c a ticket. Thirty beer gardens (until they were destroyed during the recent riots in Soweto[4]) made profits for the W.R.B.A.A.B. and these profits were reinvested in the development

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4. See page 46 of the present study.

of the area and solubilisation of tsamboek. The breeding of bees is a source of income in some families and the product is sold in "shebeens" or illicit taverns. There are also seven bar lounges in Soweto.

3.10 Religion

There are 299 church buildings in Soweto (W.R.B.A.A.B. Annual Report, 1975) and 70 recognized denominations. Many religious groups have come into existence over the last few decades. These groups are known as African Independent churches, and the number for Soweto is estimated as 900 (N.E.A.D. Research Reports, 1973). The African Independent churches combine, in different degrees, elements drawn from traditional Christianity, ancestral worship and from magical systems of thought.

3.11 Some Social Problems

The crime rate in Soweto is high. In answer to a question in Parliament in April 1975, the number of murders for the year ending 30 June 1974 in Soweto was reported as 854. Rape also occurs with a high frequency, the figure for the same period being 1282. There were also 7 682 reported assaults with intent to do grievous bodily harm (Horrell and Hodgson, 1976).

Problems of family disorganization, juvenile delinquency, child neglect and truancy occur, as do psychiatric and adjustment problems. One of the biggest problems, however, is that of the thousands of children who drop-out of school at too young an age to be employed. In the words of Hellman (1971, p. 18) the problem is one of 'young people who have grown up in a moral no man's land, ... in a society in which traditional sanctions do not and

cannot operate to control behaviour, in which new norms are as yet in the process of development'. Some of the young people do adjust within this society but others become gangsters, or, in the vernacular, 'tsotsis', terrorising their neighbourhoods.

3.12 Social Work Services

Central and local government as well as private welfare organizations provide social work services to the people of Soweto. The W.R.B.A.A.B. employ thirty-one black social workers and eleven white social workers[5] to work in the area. Many of the large predominantly white welfare organizations, such as the Child Welfare Society, Mental Health Society and Cripples' Care Association, also employ black social workers to operate in Soweto. There are social workers attached to Baragwanath and St. John's Eye Hospitals. A number of Church bodies have social workers whose duties include poor-relief work such as the provision of food parcels, clothing and the payment of rent and school expenses. Social workers assist with application for government pensions which are available for the aged and handicapped.

The new Council of Voluntary Social Services in Black Communities was constituted in August 1976. This body will facilitate the co-ordination, co-operation and communication between community social services in Soweto, and will, in time, be able to assess needs, ascertain priorities and mobilise the development of new resources. The initiation of this Council should have long-term beneficial implications for many different medico-social as well as purely social services.

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5. These white workers, however, have not been permitted to enter Soweto since the riots in Soweto in June, 1976, see page 46 of the present study.

Other social welfare organizations are in the process of developing; for this purpose a new concept of service, divorced from personal considerations of reward or kinship ties, is being stimulated in the black community. 'African self-help' groups particularly are being organized to assist in improving the quality of life of the people of Soweto.

3.13 Some Aspects of the 1976 Soweto Unrest

The disturbances in Soweto in 1976 have bearing upon this study since they were initiated in the first instance by the youth of Soweto. The unrest was originally stimulated, overtly, by the disapproval of the language policy, whereby black scholars were taught some subjects through each of the two official languages of the country (English and Afrikaans). As a result of the student unrest there was widespread damage to property. In the month of June 1976, alone, all twelve W.R.B.A.A.B. offices were destroyed; all beer halls, except one, were gutted; the bank, library, telephone exchange, seven post offices and 50 shops were set alight and plundered. Two clinics were gutted and one clinic, as well as the Early Learning Centre in Soweto, was damaged. Then there was damage done to 70 buses and to railway signals. The official June death toll was 176 (Race Relations News, 1976). There were also strikes and many working hours were lost.

One of the most disturbing consequences was the evidence of the visible absence of parental control over the Soweto youth and the break-down of communication and trust between parents and children. On being interviewed by reporters many young people stated that they blamed their parents for having given in to the system, that they felt their elders were powerless and that if

they wanted things done they would have to act themselves (Race Relations News, 1976).

3.14 Conclusion

Soweto has been called a city within a city (Louis, 1966, quoted by Hellman, 1971). It has a symbiotic relationship with the predominantly white city of Johannesburg. It is dependent on Johannesburg for its very livelihood and Johannesburg is dependent on Soweto for its work force. Soweto is also an insecure city where rapid urbanization and social change are causing disorientation of the individual, disruption of the family and profound human maladjustment.

Soweto's problems are multiple and this discussion deals with them only briefly and very superficially. The prevailing social conditions do, however, affect the lives and well-being of every member of the society and constitute the backdrop of the field-work within the present study.

CHAPTER 4

METHODOLOGY AND PROCEDURE

4.1 Introduction

In order to collect information with respect to the aims of the present study on the young albino in Soweto a programme of field-work was designed. The original plan was to interview subjects from an albino and control group using a standardized schedule on adjustment and attitudes covering the required areas and applicable across a cultural barrier. If it was not possible to find such a schedule the writer would construct a schedule and this would be put to a pre-test in a pilot study using a group of teenagers, excluding albinos, selected randomly from the school population of a mixed class area in Soweto. The results of this preliminary investigation would be examined particularly in regard to any inconsistencies in the schedule. Items found to be unreliable or non-discriminatory would be dropped. The schedule would be altered accordingly and would then be used in a face-to-face interview situation with each subject in the albino and control group, by a selected black interviewer. The control group would be normally pigmented and matched according to certain criteria.

The schedule would be scored by the writer and submitted to statistical analysis in order to identify any significant differences between the two groups. The results and conclusions would be based on the information obtained in this way.

The methodology and procedures used during the various stages of the field-work are described in this Chapter.

4.2 Ascertainment and Selection of Experimental Subjects

Prior to the initiation of the present study the majority of the albinos living in Soweto had been located by the writer. Several methods were used for this purpose.

(1) Every school in Soweto was visited, the School Principal was interviewed, albinism was described and enquiries made about any pupils who might have the disorder. If an albino child was present in the school he was called to the principal's office, his name and address taken and his parents visited. In this way 120 (the total number at the time) Soweto schools were visited and 105 000 children screened.

(2) All the clinics were visited and albinism was discussed with the staff. They were issued with blank lists and asked to complete details of names and addresses of any albinos requesting treatment.

(3) Baragwanath Hospital and St. John's Eye Hospital were visited and the key staff members there were informed of the nature of albinism and asked to keep a record of any albinos attending the hospitals.

(4) Social workers in W.R.B.A.A.B. service in Soweto were made aware of the survey and were asked to keep a note of any albinos they encountered.

(5) Albinos and their families were asked to notify the writer of other families with affected members known to them.

(6) For the duration of one school holiday an albino student (who was completing his final year at High School) was employed to stand at the stations in Soweto to get the names and addresses of any albinos who were commuting to work each day and might be missed by the other methods of ascertainment.

(7) Letters were written to all the Welfare Organizations dealing with blacks in Johannesburg requesting their co-operation in the survey, and asking them to notify the writer of any of their albino clients or contacts.

The result of these investigations was that over 200 albinos of all ages were located. Their homes were visited and details of age, sex, education, and the history and composition of the family, were recorded. Problems were noted, and social work services, which were an integral part of the research on albinism, were

offered, and referrals to relevant Welfare Organizations were made.

The availability of this information concerning the albinos in Soweto facilitated the selection of subjects for the present study. Initially it was planned that all the albinos born between the years 1952 and 1960, and living in Soweto, and who could be classified according to the definition of Albinism in Chapter 1, should be included as subjects. The methods of ascertainment for these subjects are shown in Table 4.1. Many of the albinos in the survey of

TABLE 4.1. METHODS OF ASCERTAINMENT OF ALBINO SUBJECTS

SOURCE	NO. OF ALBINOS (N = 35)	PER CENT
School	29	82
Health Clinics	10	28
Welfare Organizations	8	23
Other Families with Albinism	8	23
Hospitals: St. John's Eye	6	17
Baragwanath	1	2
Municipal Social Workers	4	11

Soweto had double or treble ascertainments and the number of ascertainments for the subjects for the present study is shown in Table 4.2. About 65 per cent of the subjects had two or more ascertainments and this information indicates that the likelihood that any albinos in this age group were missed is reasonably small.

The thirty-five albino subjects selected in this way represented the experimental group. They were divided into three sub-groups: namely Higher Primary School scholars, High School scholars and 'drop-outs'. This latter group had been at school for shorter or longer periods of time and had dropped out for a variety of reasons, such as economic pressure, academic failure or pregnancy. Some

members of this group had sought employment unsuccessfully, others had been employed briefly, but they were all unemployed at the time the interviews for the present study were carried out.

TABLE 4.2. NO. OF ASCERTAINMENTS OF ALBINO SUBJECTS

	NO. OF ASCERTAINMENTS				TOTAL
	1	2	3	4	
No. of albinos	12	15	7	1	35
Percentage	35	42	20	3	100

The albino group was interviewed first and the age, sex, educational standard, and status as scholar or drop-out, of each subject was ascertained for the purposes of selecting matched control subjects.

4.3 Selection of the Control Group

'Pairing can improve the probability that two groups are matched for the purposes of experimental comparison' (Hilgard, 1966, p. 536). Therefore the pairing method of selection of the control group was chosen for the present study. Four basic criteria were used for the purposes of matching:

(1) Age, to the nearest year.

(2) Sex.

(3) Educational level, according to the current standard achieved, or the level at which the subject dropped out.

(4) Occupational status, in this case either scholar or drop-out and unemployed.

The information on these criteria was obtained on each albino subject and a normally pigmented control subject, who matched each albino subject as closely as possible on all four criteria, was selected. Four criteria was considered a maximum since, as

Jahoda *et al.* (1952) state, matching with any degree of precision on more than two or three factors is rarely possible.

In order to obtain suitable subjects to match the scholars in the albino group, a Higher Primary and a Junior High School were approached. The principals of the two schools were asked to draw up lists from the class registers, of any three pupils matching each experimental subject by sex, age and standard of education. From this list the writer selected the subjects to be interviewed by writing the three names on pieces of paper of equal size, folding and shuffling them and asking the interviewer to draw one out. In this way a paired, matched and randomly selected, control scholar was chosen for each albino scholar.

It was more difficult to select paired and matched controls for the subjects in the Drop-out group. For this purpose a street in Soweto was selected at random and house to house visiting undertaken to find young blacks who were unemployed and not at school. For each albino subject it was only possible to find two reasonably closely matched control subjects in the area. Of these, one was selected using the method described above for the school-going group.

When the selection procedure was completed the control group of normally pigmented subjects was interviewed. The groups were carefully matched in order, hopefully, to eliminate the operation of any unnecessary and uncontrolled variables, leaving skin colour as the major difference between the two groups.

4.4 Selection of Interviewers

'It is widely accepted that black interviewers are used with black subjects on the assumption that solutions to problems of language and trust are facilitated' (Glass, 1962, p. 137). For this reason,

and because the albino subjects were known to the writer, whereas the control subjects were not, black interviewers participated in the present study.

It was not possible for the interviewer who conducted the pilot survey to proceed, so a second interviewer was appointed for the final study. Both interviewers were, however, graduates in the social sciences with experience in interviewing. The interviewer for the pilot study was male and for the final study the interviewer was female.

Both interviewers were proficient in several Bantu languages. It was agreed therefore that the schedule be translated into only one Bantu language, namely Sotho, (see Appendix F, for this translation) and that the interviewers would use this translation for a clear understanding of the concepts involved and for the purposes of checking on the few words with which they were unfamiliar. They would conduct the interviews in the language of the subjects, using the English schedule, and would translate the subjects' responses into English and note them on the schedule form, in the appropriate places.

The interviewers were both fully instructed on the nature of albinism and on the previous studies, carried out locally, of the albinos in Soweto. They also participated in discussions on the construction of the schedule and the suitability of various items for use in the Soweto community. They were thus well aware of the background of the present study before proceeding to undertake the interviews.

4.5 Selection of an Appropriate Schedule

With the aims of the present study, as well as its setting, selected

subjects and prospective interviewers, in mind, the writer searched for a suitable schedule. Buro's (1970) Mental Measurements Year Book was consulted. Several questionnaires and schedules were considered viz.: Bell's Adjustment Inventory (1962), the California Psychological Inventory (C.P.I.), the Minnesota Multiphasic Inventory (MMPI), the Maudsley Personality Inventory, the Science Research Associates' (S.R.A.) Youth Inventory (1956) and Cattell's 16 Personality Factor Questionnaire (16 P.F.). Numerous problems were met with in trying to adapt these tests to the local setting. For example Bell's Adjustment Inventory was found to be too long and many details in the wording of the items would not be relevant or applicable in the life experience of the local young black person; the C.P.I. has 480 items, which is too lengthy to be used in an interview, particularly where translation is required; the MMPI was too clinically orientated and only suitable for the over 16 age group; Eysenck's Maudsley Personality Inventory measured only two personality factors, i.e. neuroticism and extraversion-introversion, and was not sufficiently extensive to cover the aims of the present study; the SRA youth invencory on the other hand covered too many dimensions and required responses in writing, which method was not considered suitable for the partially unsophisticated population being studied here; Cattell's 16 PF has a form X for semi-literate or illiterates, but this has not been standardized for use in Africa, and would not have been suitable for the better educated subjects in the present study.

The Structured and Scaled Interview to assess Maladjustment (Gurland *et al.*, 1972) was considered, but although it included five major fields of life adjustment, these did not include physical health. The items were chosen to meet the authors' concept of

maladjustment which to them 'includes problems of both objective behaviour in a given social context and of subjective reactions in that context', and to assess dev. nt behaviour, friction with others and subjective distress. This distress involved mental or emotional but not physical distress, which was considered important for the present study. The possibility of using this schedule was thus rejected.

No suitable reliable validated schedule could be found and so the w.i.er decided to formulate a sch dule of items, using her own experience as well as advic from local experts, and i luding selected items frequently found in some of the questionnaires a schedules mentioned above.

4.6 Construction of the Schedule

The aim in constructing the schedule was to present, not a technique of testing ready for applied psychology, but simply a method of enquiry suitable for the collection of d ta relevant to the present study. The interpretations of the results of such a schedule would be confined to the differences between groups; individual predictions and diagnoses would not be undertaken.

The writer then selected items for pre-testing in a pilot study. Items which were easily understood and translated and which led to responses differentiating well between two groups of people would be retained as good items and carried forward to the final form of the schedule. If more than 95 per cent of the responses were identical the item would be dropped as a non-discriminatory item. This method was based on that used in the compilation of items for the MMPI and the writers, Hathaway and McKinley (1960, quoted by Buro, 1965), emphasized that assumptions need not be made as to

whether the subject has insight into the meanings of the items or into his own dynamics in responding to the items.

The schedule was constructed in three sections:

I Items relating to the identifying information on the subject.

II Items concerning problems in the areas of physical, interpersonal and emotional dimensions of adjustment.

III Items concerning attitudes towards albinism and towards a social work service.

4.6.1 Section I : Identifying Information

The first section was concerned with the gathering of identifying information on the subjects, in order to construct a social profile of both the albino and control groups. The items for this section were derived from the short index of adjustment from the Mental Examiner's Handbook (Wells and Ruesch, 1960), and may be seen in Appendix A. One item, concerning the status of the subject as either an albino or a control, was added. Also the categories of skin and eye problems were included in the item concerning medical history, as these categories are particularly associated with albinism. Interest in sport, as an active pastime, and radio as a sedentary pastime were incorporated in the item on interests. In addition the responses to this item on interests were divided into two groups i.e. 'alone' or 'with friends', in an attempt to establish whether albinos seek isolation rather than company.

4.6.2 Section II : Adjustment

For the purposes of the selection of items for the second section of the schedule, adjustment was defined according to the definition of English and English[1].

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1. See page 13 of the present study.

In order to pursue the aims of the study items were selected to cover the interpersonal, emotional and physical aspects of adjustment. Items on these three areas constituted the sub-scales of the schedule.

Sources consulted for the selection of the items included the following:

(1) Bell's Adjustment Inventory (1934 and 1960): Bell selected items concerned with the four areas of home and family, health, social and emotional adjustmen .

(2) The Science Research Associates Youth Inventory (1956).

(3) Woodruff's (1948) common indicators of maladjustment in young people (see Appendix B).

(4) A black clinical psychologist working amongst the people of Soweto.

(5) Two experienced and well-qualified staff members, one black and one white, of the National Institute for Personnel Research in Johannesburg.

(6) The academic supervisors of the present study.

The list of items selected for the three sub-scales and their source of origin may be seen in the Tables in Appendix C. Once the items had been selected they were reworded so that there would be no positive or negative bias and no response set could be established (Oppenheim, 1960). The items from the three sub-scales were then scrambled, so that attention would not be directed to any one area. Two items were inserted near the end of this section in an attempt to find out whether the subjects themselves emphasized problems in any particular area of adjustment.

The items in this section required a 'Yes' or 'No' response. In addition, on fifteen items the dichotomous response was followed by a 'Why' and the interviewer was requested to probe for further information which might be relevant to the adjustment of the subject.

It should be emphasized here that these items were selected for

an exploratory study into the adjustment of the albinos and controls, and that once the results were available many improvements could be made on the actual nature, suitability and conciseness of the items. It is also necessary to point out that the items were to be used in a face-to-face interview, with the interviewer translating each item into the language of the subject during the course of the interview. Each item therefore had to be worded as briefly and clearly as possible and the overall number of items kept to a minimum.

4.6.3 Section III : Attitudes

The third section of the schedule was designed to explore attitudes towards albinism and the subjects' views on social work services and what these could offer. This section was connected with Section II by introductory remarks concerning the writer's interest in albinism in Soweto and the need to have further items on this subject[2].

The majority of the items for Section III were derived from the work of Adorno *et al.* (1950) on the prejudiced personality. Some of the items were open-ended, others required a 'Yes' or 'No' response, which was followed by 'Why', and the interviewer was instructed to probe to obtain the maximum information. Since the topic was likely to be a sensitive one, the wording of items was carefully considered. The first three items were of a general nature to encourage the subjects to talk freely, thereby hopefully reducing defences as well as guilt and anxiety about the topic, and producing more reliable information concerning attitudes towards albinos.

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2. See the final form of the schedule, Appendix H, for the wording of these remarks.

A few items in this section were included to indicate whether or not there were common beliefs which would presumably influence the attitudes being expressed. Others attempted to establish the beliefs concerning the etiology and inheritance of albinism.

Finally there were items relating to a social work service and suggestions were requested as to how the social worker could help with problems.

Several items for this section were selected from the schedule of Adorno *et al.* (1950) and from the experience of the writer. Other items were the outcome of discussions with the clinical psychologists mentioned above, with the supervisors of this study and with the staff of the Department of Social Anthropology of the University of the Witwatersrand. Details of all the items in this section and their sources may be seen in Appendix D.

At the end of Section II the interviewer was asked to comment, in writing, on the ease or difficulty of the interview and the facility with which the subject expressed himself.

Once the selection of items had been completed for each section and incorporated in the schedule (the total number of items was 55), the general introductory remarks were drawn up. These remarks included an explanation of the writer's designation and purpose in conducting the study, as well as encouraging the subject to co-operate thoughtfully, honestly and truthfully (based upon Bell's introductory remarks to his Adjustment Inventory, 1934). The schedule, in the form in which it was used in the pilot study, may be seen in Appendix E.

4.7 Procedure of the Study

The constructed schedule was used by an interviewer in interviews

with fifty randomly selected normally pigmented subjects in the pilot study. On the results of this study (which will be described in detail in Chapter 5) the schedule was improved and expanded. The final schedule was then used in interviews with thirty-five albino and thirty-five normally pigmented control subjects. The responses of the two groups were scored and submitted to statistical analysis. The groups were compared and significant differences computed and discussed. The schedules were then taken to two independent clinical psychologists, who examined the responses to the 'Why's' on the adjustment items in Section II of the schedule, and made a blind assessment of the levels of adjustment of the two groups. Detailed case studies were carried out on two subjects by the writer. The subjects selected for this study were a high scoring or relatively well adjusted subject and a low scoring or relatively poorly adjusted subject. The conclusions were based on the information gained from these three sources i.e. the statistical analysis of the data, the clinical psychologists' assessment and the two case studies. Needs and problems as established from the results were discussed and suitable responses for the social worker determined.

4.8 Scoring of the Final Schedule

The responses obtained on the final schedule were scored by the writer throughout. The scoring methods varied, as did the statistical tests used, according to the requirements of the section under attention.

4.8.1 Section I

Section I contained identifying information on the subjects and

results were obtained by means of frequency counts and tabulations. The appropriate Sign test for comparing frequencies in two related samples (Connover, 1971, p. 127) was used by the writer to analyse the data obtained. Differences were accepted as significant if $p < 0.05$.

4.8.2 Section II

Section II contained items, concerned with adjustment, which required dichotomous responses. Quantification was an arbitrary matter of assigning weights involving successive integers. Goode and Hatt (1952, p. 273) stated that the use of a simple method of scoring such as giving the favourable position a weighting of one is acceptable. Rundquist and Sletto (1936, p. 98) have examined this method of scoring, together with a method involving the weighting of each item differently, and found a positive correlation between the two methods of > 0.95. Their study gives strong empirical support to the use of simple methods of scoring.

Adorno *et al.* (1950, p. 327) scored their schedules in terms of a three-point scale, high (indicating the prejudiced), neutral, and low (indicating the non-prejudiced). Similarly Cattell (1965, p. 240) used a simple 2-1-0 method of scoring his 16 PF Questionnaire, the right answer scored 2, the intermediate scored 1, and the wrong answer 0. Finally Anastasi (1970, p. 419) agreed that scoring using three crude categories is acceptable.

Having accepted a three-point scale as a suitable method of scoring the problem was where to place the 'no information' or 'don't know' responses. Oppenheim (1966, p. 237) states that it is legitimate to group the 'don't knows' with 'no answer' and these two categories are frequently grouped together. A 3-2-1 scale

was therefore used, where 3 was a positive response indicating good adjustment, 2 a neutral or intermediate position (including the 'don't know' and 'no information' responses), and 1 was a negative response indicating maladjustment. The writer scored the schedules with this scoring system and proceeded to use the method of summated ratings (Triandis, 1971, p. 42) for an item analysis to contruct a Likert type scale. The final scores of the subjects in the two groups were based upon their responses to the retained items on this scale.

Prior to analysis of the data the levels of significance were determined. According to Siegel (1956, p. 9) 'the level at which the researcher chooses to set X (the level of significance) should be determined by his estimate of the importance or possible practical significance of his findings'. The writer therefore decided to work at the stringent level of $p < 0.01$ when selecting items to be retained on the Likert-type adjustment scale. This level of significance was selected in order to obtain a more reliable scale. However differences between the experimental and control group were accepted as significant if they reached the conventional level of $p < 0.05$.

To produce a schedule which showed internal consistency Likert's (1932) method of item analysis using summated ratings as described by Triandis (1971, p. 42) was applied to the data. Every item in each schedule was scored according to the 3-2-1 point system outlined above. The subjects were then ordered according to their total scores. The experimental and control group were pooled, those subjects who had scores that fell in the top quartile (25 per cent) of the scores were called High Scorers, and those who had scores falling in the lowest quartile

(25 per cent) of scores were called Low Scorers.

For each item the mean score of the High Scorers was computed and compared with the mean score of the Low Scorers. This difference was called the Discriminatory Power (D.P.) (after Adorno *et al.*, 1950) and the D.P. value for each item was computed. All those items with D.P. values which did not meet the required level of significance ($p < 0.01$) or with negative D.P. scores, indicating that the Low Scorers had scored higher on the particular item than the High Scorers, were rejected. The result was that a Likert-type scale with some measure of internal consistency was constructed.

A matrix was drawn up with the scores of the experimental and control subjects for the remaining items on the scale. The scores of the two groups were compared, on the overall totals, by sub-groups i.e. higher primary school, high school, and drop-out subjects, for male and female subjects, and on each item separately.

As an additional method of scoring this section and to obtain further information relating to the adjustment of the subjects, two independent clinical psychologists were asked to act as judges and to rate the responses obtained from the 'Whys' appended to certain items. They were required to rate these responses on a seven-point scale, according to whether the response indicated good adjustment (scored 7) or poor adjustment (scored 1), with reference to the definition of adjustment given in Chapter 1 of the present study[3]. (The detailed instructions given to the judges appear in Appendix G). The ratings for each subject on each item were totalled separately for each judge, by the writer, and correlation

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3. See page 13 of the present study.

coefficients between the two judges were computed. The scores for the experimental and control groups were compared by means of the 't' test for matched samples (for the method used see McCall, 1970, p. 188).

4.8.3 Section III

The responses to fourteen of the items in Section III were scored by the writer with the same method used for the items in Section II. These fourteen items were concerned with attitudes towards albinism, and the three-point scoring system was used where a score of 3 indicated a positive attitude towards adjustment, 2 a neutral attitude (including items for which there was a 'don't know' response or no information) and 1 a negative attitude. Once the scoring had been carried out, an item analysis using Likert's method of summated ratings, as described above, was undertaken. Some items were subsequently rejected and a scale with some measure of internal consistency was constructed. The scores on this scale were treated in the same way as those in Section II, the two groups were compared and the relevant 't' tests for matched samples (McCall, 1970, p. 188) were computed to indicate where there were significant differences between the groups.

Eight further items in this section were used to collect additional information for descriptive purposes only. Frequency counts, together with the Sign test for comparing frequencies in two related samples (Conover, 1971, p. 127) were carried out where applicable.

Once the scoring of the schedule and the statistical analysis had been completed the results could be deduced and conclusions drawn.

4.9 Summary and Conclusion

For the purposes of obtaining reliable information in the areas under investigation for the present study, it was necessary to use a scientific method in planning the field-work. The selection of subjects was limited to the twelve to twenty-one year old age group, and matching on predetermined criteria was required for the control group, to eliminate unnecessary variables. The interviewers were chosen from highly educated, experienced people and were fully informed as to the nature of albinism and the purposes of the present study. It was found necessary to construct a schedule and this was undertaken with reference to other reliable and frequently used schedules and questionnaires, as well as in consultation with several experts in the fields of research and psychology in the local black community. The schedule was completed in interviews with the subjects in the vernacular, by black interviewers. The responses obtained were scored and analysed. The albino and control groups could then be compared, any significant differences between the two groups ascertained, results drawn up and implications of the findings outlined.

CHAPTER 5

THE PILOT STUDY[1]

'A pilot study or pre-test, where the schedule items are tested on a sample as much like the sample that will be studied as possible, often precedes the actual use of the schedule'. (Goldstein, 1963, p. 129). This type of preliminary study was considered a particularly necessary step in the present study, since it was exploring new areas of investigation with a previously untested series of items. The pilot study therefore required specific aims, a selected group of respondents[2], an experienced interviewer who was carefully instructed, an analysis of the results from the responses to the draft schedule, a discussion on the implications of the findings, and the subsequent amendment of the schedule.

5.1 The Aim of the Pilot Study

The purpose of the pilot study was primarily the testing and refining of the newly constructed schedule and the subsequent designing of a more adequate and reliable measuring instrument.

The aims were four-fold:

(1) To check the schedule for length: 'For most purposes an optimum length for an interview is 20-30 minutes, but some may last an hour. One of the objects of the

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1. The term 'pilot-study' was used here in a limited sense to refer to a test of the schedule or instrument itself, and did not include 'the completion of all the phases of the study on a small sample' (Goldstein, 1963, p. 129), which is the conventional meaning of the term. The word 'pre-test' might have been preferable, but is not commonly used or readily understood.

2. The term 'respondents' was used to refer to the young people who participated in the pilot study, as opposed to the term 'subjects' which was used for those who participated in the final study.

pilot study r . on a new questionnaire should be to check it for length' (Stacey, 1969, p. 84). Several aspects were involved here : the schedule should not be too long to become cumbersome, because of the simultaneous translation into the vernacular which was required; it should not be so long that the likelihood of 'fatigue effect' was increased; but should be sufficiently long to obtain data concerning all the aims of the present study.

(2) To determine which items required modification or elimination : since the present study was being conducted across a cultural and language barrier, the writer was aware that the respondents might not understand items as they were intended to be understood when constructed. Inconsistencies in responses might be discovered, as well as ambiguities, and difficult or poorly worded items which might lead to inadequate or misleading responses. Some items might require modifying and others might be substituted with more suitable items. The introduction of new items might be required to clarify a particular area of investigation.

(3) To determine the nature and extent of the translation problems : although the interviewer was proficient in several of the languages commonly used in Soweto, and had the Sotho translation of the schedule available to consult, translation problems might occur with certain items. The interviewer, being academically well qualified and experienced, might clearly understand an item, but might find difficulty *in situ* in translating and communicating simply the meaning of an item to the respondent. It might become necessary to make further translations, into other major Bantu languages, for the use of the interviewer.

(4) To ascertain marginal comments from the interviewer, and clarify and deal with any unexpected difficulties encountered. Particularly it was anticipated that there might be difficulties and resistences in interviews with respondents in the younger age groups. As Vernon has stated, (1964, p. 270) the self concepts of young adolescents or pre-adolescents are 'too vaguely formulated for their responses to represent anything much beyond the top level of Self'.

5.2 Selecting the Sample

In order to compile data on the aims of the pilot study, it was necessary to select a sample which was representative both of the population from which it was selected, and in terms of the variables important for the present study. Since the majority of the subjects

for the final study were scholars it was planned to select the sample in a random manner from the school population of Soweto. The sample was required, however, to show the same distribution as regards age and range of educational level as the experimental subjects for the final study, and to be composed of both males and females.

The size of the sample was carefully considered. Since a 'relatively small increase over the basic minimum of twenty-five to thirty produces a considerable decrease in error' and since in social work 'samples of fifty to one hundred are common' (Goldstein, 1963, p. 113), the number of fifty subjects was determined as adequate for the pilot study.

The stratified method and the simple random sampling method (Goldstein, 1963, p. 117) were used in combination to obtain the sample. The population was stratified according to educational level and sex, and since the school population in the two selected schools was composed of more females than males, this distribution was maintained in the sample. From the school registers lists were drawn up for males and females and subjects were numbered and selected from each class by means of a table of random numbers.

In order to approximate the distribution of educational level in the group of final subjects, the sample was composed of thirty-five scholars from the Std. III to Std. VI in the Higher Primary school and fifteen scholars from Form I to Form V in the High School. Some classes in the schools contained larger numbers of scholars than others and the sample was weighted to represent this distribution. Since educational level is more or less dependent on age, no further steps were taken to control the variable of age for the pilot study. The composition of the pilot study sample, in comparison with the albino subjects for the final study, may be seen in Table 5.1.

TABLE 5.1. COMPOSITION OF THE PILOT STUDY SAMPLE IN COMPARISON WITH ALBINO SUBJECTS

SCHOOL CLASS	MALES		FEMALES		NO. OF ALBINO SUBJECTS	TOTAL NO. IN PILOT SAMPLE
	NO. IN CLASS	NO. IN SAMPLE	NO. IN CLASS	NO. IN SAMPLE		
Std. III	75	5	103	6	9*	11
Std. IV	70	4	64	3	2	7
Std. V	55	3	90	6	8	9
Std. VI	62	4	87	4	6	8
Higher Primary School Total:	262	16	344	19	25	35
Form I	148	2	176	2	5	4
Form II	103	1	176	2	2	3
Form III	160	2	187	2	2	4
Form IV	148	1	105	1	1	2
Form V	99	1	47	1		2
High School Total:	658	7	691	8	10	15
Total:		23		27	35	50

* Six subjects in the albino group had an educational level of less than Std. III, but were included in this table in the Std. III group.

5.3 Selection of and Instructions to the Interviewer

A trained and experienced black interviewer, proficient in several Bantu languages, was selected to conduct the interviews with the respondents, using the schedule prepared for the pilot study.

Prior to the commencement of the interviewing several discussions were held with the interviewer. One of the most important aspects of these discussions was clarifying the interviewer's own feelings on the subject of albinism, so that he would not sub-consciously introduce bias into the situation. The interviewer must 'become alert to what he is bringing to the interview situation .... his intonation, his fears and anxieties, his obtuseness and his cleverness' (Goode and Hatt, 1952, p. 187). The condition of albinism, its cause, and attached problems were explained to the interviewer, as was the purpose of the present study and the outcome of previous studies on the subject.

The interviewer was also involved in item selection and decisions regarding translations of the schedule into a Bantu language. The Sotho language was selected because the pilot study interviewer felt this was the language in which he was least proficient. Individual items were discussed with the interviewer and underlying concepts clarified where necessary.

Finally instructions concerning the pilot study were given to the interviewer. He was required to complete a schedule with each of the selected respondents in the relevant vernacular and to record the responses in English in the appropriate places on the schedule. He was asked not to accept 'Don't know' responses too easily and to probe when necessary. He was required particularly to note the four-fold aim of the pilot study and to record the time taken for each interview, to note the items which the respondents had particular

difficulty in answering and consistently misunderstood; to comment on translation problems; and to note any other problems he might encounter, particularly during the interviews with the younger respondents.

Since the interviewer was experienced, it was not necessary to instruct him regarding interviewing techniques or methods of establishing rapport and motivating the respondents so that they responded thoughtfully.

The instructions for the respondents concerning the study were presented on the front sheet of the schedule, and the interviewer was expected to go through these with each respondent, as well as through the few remarks at the beginning of the third section on attitudes to albinism. The interviewer was required to return the completed schedules to the writer in person.

5.4 Procedure

Once the pilot study schedule was ready to be tested, the methodology of sampling determined and the interviewer instructed, the writer selected two schools, a higher primary and a high school, from which the sample would be drawn. The two schools were sited in mixed class and language suburbs of Soweto, they were easily accessible and the principals and staff were co-operative. There were albinos attending both schools, so the scholars had been exposed to the condition and should have a certain amount of familiarity with it. The sample of fifty respondents was then selected by the predetermined methods. The structured interviews were carried out by the interviewer using the draft schedule. The completed schedules were returned to the writer and were submitted to limited analysis for the purpose of obtaining information on the aims of the pilot

study. Each item and the responses were examined. Discussions were held with the interviewer and his comments were carefully considered. With the results from these sources available, the schedule was re-drafted in readiness for the final study.

5.5 Results

The results were based on an examination of the responses obtained from the pilot study interviews, on the marginal comments and notes of the interviewer, and on discussions with him concerning the value of each item. The results, pertaining to the aims of the pilot study, were as follows:

(1) The length of the schedule : 94 per cent of the respondents took less than 30 minutes to respond to all the items on the schedule. The mean time taken for the subjects from each school class may be seen on Table 5.2.

TABLE 5.2. MEAN TIME TAKEN PER INTERVIEW WITH PILOT STUDY SCHEDULE

	NO. OF SUBJECTS	MEAN TIME (IN MINUTES)
Std. III	11	18.8
Std. IV	7	23.6
Std. V	9	22.9
Std. VI	8	21.2
Form I	4	25.2
Form II	3	22.3
Form III	3	25.0
Form IV	2	25.0
Form V	3*	31.6

* One male subject in Form III was unavailable at the time of interviewing and was replaced, by the interviewer, with a female in Form V.

The interviewer expressed the opinion that both he and the respondents found the schedule most interesting and not too long. He stated that several respondents asked if they could not answer more questions, and he considered that further items could be included without the danger of increasing 'fatigue effect'.

(2) Items requiring modification: when responses were examined three items showed that more than 95 per cent of the respondents had replied in one direction. This tendency may have indicated a norm in the population, on the other hand the items may have been too easy or too difficult to answer. One of these items was also double-barrelled and this might have caused a problem. Another appeared to be meaningless in terms of adjustment ('Do you ever have colds?) and had to be expanded to: 'Do you often get sick, so that you have to stay away from school/work?'

The interviewer noted that three further items had given difficulties in the interview:

(a) 'Do you feel self-conscious because of your appearance?' The subjects apparently understood this item as involving a feeling of self-awareness rather than self-consciousness, shame or embarrassment'. The item was reworded 'Are you ashamed because of your physical appearance?'

(b) 'Do you feel you don't belong in your family?' Yes/No. This item presented problems because of the double negative, several respondents responded 'Yes' and when asked to elaborate, explained that they were very happy at home with their family. The concept of belonging was difficult to communicate, many subjects implying that it was natural to belong in the family, they were of the same blood as parents and siblings. This item was therefore clarified: 'Do you feel wanted and needed by your family?'

(c) 'What are your main problems?' The interviewer had difficulty in obtaining responses to this item, many said they had no particular problems. The item was reworded: 'What troubles you most often?'

(3) Translation problems: some of the items mentioned above produced translation problems. For example feelings of belonging and of self-consciousness were difficult to communicate in the vernacular.

Also, to seven adjustment items in the pilot schedule, responses were required in the form of 'often', 'sometimes' or 'never'. The interviewer had difficulty in getting the respondents to make the fine distinction between these three alternatives. It was decided therefore that dichotomous responses should be used throughout, with a 'Why' attached where further information would be useful.

Several other words were not translatable. For example the word 'easily' had to be deleted from the four items in which it appeared. The word 'normally' created problems and the item 'Should albinos live normally like other people?' had to be altered to 'Can albinos live like everybody else?' Similarly the word 'avoid' was not readily communicated and the item 'Do you avoid other people?' was eliminated.

The possibility of translating the schedule into other Bantu languages was considered, by the interviewer and the writer. The idea was discarded, however, since the interviewer was of the opinion that official translations were usually too formal and he would have to use colloquial language with the young subjects during the actual interviews.

(4) Interviewer's comments: The interviewer's comments were favourable, he stated that with the problems as outlined above, resolved, the schedule could be applied to the experimental and control group subjects. He reported that he had not experienced any difficulty in establishing and maintaining rapport and that the majority of the respondents had been happy to participate and showed interest in the study. He added that in many cases more information had been volunteered than had been required, and that 'Whys' could be appended to several other items. This finding was supported by Biesheuvel's (1958, p. 170) suggestion that

> 'A host of cultural circumstances may interpose themselves between the questioner and his subject. The direct, concrete, question and answer approach may not commend itself to certain African cultures, which may prefer communication by way of allegory or fable, understood only by those who have an intimate knowledge of a culture'.

'Whys' were subsequently added to fifteen adjustment items and nine attitude items. A further nine attitude items were open-ended.

Finally the interviewer commented that the younger respondents (ten, eleven and twelve year olds) had had difficulty in responding and that many of their

responses appeared to be superficial. The mean time taken by the youngest group (in Std. III, see Table 5.2) was 18.8 minutes and the interviewer thought that this was partly due to their lack of understanding of many items. He suggested that the subjects in the youngest age group i.e. 12 years and under, be omitted from the final study.

5.6 Implications of the Findings

Due to the findings as set out above, many alterations to the schedule became necessary The schedule items were again discussed with the experts mentioned above. In view of the results, and these discussions, modifications were made and several items added, some to clarify and enlarge or those items which had been misunderstood or to which the respondents had wanted to add more information.

The results showed that the schedule could be lengthened without danger of producing a 'fatigue effect' in the subjects. The area which appeared to have been neglected was that concerned with social distance and items in this area were subsequently included (with reference to Triandis, 1971), for example 'Would you eat from the same pot as an albino?', 'Would you work in the same room as an albino?', 'Would you let your child marry an albino?'. Further items concerning the common beliefs were added i.e. 'Is there any custom in your tribe that says anything about marriage (or contact) with albinos?' and 'What do you think happens to albinos at the end of their lives?'

The total number of items in the final schedule was sixty-four. The wording of items was scrutinized and ordered to avoid a response set developing in the subjects. There were nineteen negatively worded items and fourteen positively worded items in Section II on adjustment, since it has been shown that negative items are generally more discriminating.

5.7 Value of the Pilot Study

A pilot study of this nature is a crucial step preliminary to the formulation of the final draft of a new schedule. No amount of intuition, consulting of sources or experts, or systematic thought could substitute for a trial run with a sample of the same design as that to be used in the final study.

The pilot study provided valuable information on the four areas as outlined in the aims, in Section 5.1 above, with which the writer was particularly concerned. This information led to the modification of many items, the resolving of ambiguities and inconsistencies, and the construction of an improved schedule. It also encouraged the writer and interviewer, and instilled a measure of confidence concerning the possibility of using the procedure and methodology selected for the study with the required subjects. After the completion of the pilot study there was some reason to believe that there would be fewer problems with the schedule in the final study and more reliable and accurate information would be obtained.

A great deal of interesting information was obtained in the pilot study but, for the present study, only the results pertaining directly to the schedule and its required modifications were relevant.

5.8 Summary and Conclusion

The carrying out of a pilot study was an integral part of the research design for the present study. The necessity for such a study was caused by the construction of a schedule of items covering a new area of research. The purpose of the pilot study then was to test the schedule, particularly as regards the length, the modification of items, the translation difficulties and the

interviewer's problems. On the results of the information obtained, amendments were made and a better measuring instrument obtained for the present study.

CHAPTER 6

RESULTS OF SECTION I OF THE SCHEDULE

6.1 Introduction

When the pilot study was completed the schedule was ready for use with the subjects in the experimental and control groups. The interviewer for the pilot study was unavailable for the final study and a new interviewer was selected, instructed and trained in the same manner as the original interviewer[1].

The new interviewer then proceeded to conduct structured interviews using the schedule with each of the thirty-five albino subjects. The age, sex, educational level and sub-group status of these subjects was ascertained and a matched normally pigmented control for each subject selected by predetermined methods[2]. These control group subjects were selected from two schools different from those used in the pilot study. Again the schools were attended by at least one albino scholar, so that the other scholars, including the control subjects, were familiar with the condition. The interviewer interviewed the thirty-five control subjects and returned the completed schedules to the writer.

The responses on the schedules were scored and analysed by the methods described previously[3] and the results were based on this work.

The results were divided into three sections corresponding to the sections of the schedule. This Chapter deals with Section I

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1. See pages 53 and 70 of the present study.
2. See page 51 of the present study.
3. See page 60 of the present study.

which contained items relating to the identifying details of the subjects, as well as their family, childhood and medical background. The following Chapter (Chapter 7) deals with results pertaining to Sections II and III of the schedule on adjustment and attitudes respectively.

6.2 Composition of the Albino and Control Groups

Initially it was planned that the experimental sample would consist of the albinos who could be classified according to Witkop's (1971) definition of albinism[4], who were born between the years 1952 and 1960 inclusive, and who lived in Soweto at the time of the present study. This group originally numbered forty altogether. Methodological considerations, however, reduced the final sample from forty to thirty-five young albinos. Two potential subjects were rejected because they were in employment and did not fit into either the scholars or drop-out and unemployed sub-group, one subject had returned to his rural area of origin and two further subjects could not be traced. The final group of albino subjects included two pairs of brothers and one pair of identical male twins.

The control group was subsequently selected and the pair of identical male twins was matched with a pair of male cousins living in the same house. Close matching of the other two pairs of brothers was not possible. The selection of the drop-out group presented some difficulties and some matches were not precise, the most extreme case was an albino who variously gave his age as between twenty and twenty-five years and had never attended school. The closest match obtainable was a normally pigmented male of approximately twenty-two years of age who had had four years of schooling.

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4. See page 7 of the present study.

The composition of the experimental group as regards sub-groups and sex is shown in Table 6.1. The composition of the control group was identical for these characteristics.

TABLE 6.1. COMPOSITION OF ALBINO AND CONTROL GROUPS

SUB-GROUP	MALE	FEMALE	TOTAL
1) Higher Primary School Scholars	7	7	14
2) High School Scholars	8	2	10
Total	15	9	24
3) Drop-outs	6	5	11
Total	21	14	35

The age and educational level of each subject was recorded in Section I of the schedule. In order to ascertain the effectiveness of the matching procedure and to give these vital statistics about the subjects this information was tabulated and is presented in Table 6.2.

TABLE 6.2. AGE AND EDUCATION OF ALBINO AND CONTROL SUBJECTS

	ALBINO (N=35)	CONTROL (N=35)
Age (in years)		
Mean ± Standard deviation	17.29 ± 2.63	16.83 ± 2.28
Education (in years of schooling)		
Mean ± Standard deviation	8.35 ± 2.06	8.11 ± 2.26

The experimental and control groups were effectively matched on all four of the criteria selected, i.e. sex, age, educational level and sub-group.

6.3 Results of Section I of the Schedule

The function of Section I of the schedule was to collect descriptive information on the albino and control subjects in respect of a number of areas.

The association between albinism and the various variables in Section I was evaluated and the significance level (p) of this association under the null hypothesis of no difference was calculated. The Sign test for two related samples (Connover, 1971, p. 127) was used for this purpose[1]. 'All tied cases are dropped from the analysis for the Sign test and the N is correspondingly reduced' (Siegel, 1956, p. 71). Consequently the numbers in the present study were less than 25 in every case, so that the test procedure for small samples was used.

Non-parametric tests were selected for the analysis of the Section I data, as well as for some of the data collected on certain items on Section III, which are reported in the following Chapter. In these cases the writer preferred to avoid making the assumptions required for the use of parametric tests[2].

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1. Professor D.M. Hawkins of the Department of Applied Mathematics at the University of the Witwatersrand assisted the writer in making decisions regarding the appropriate statistical tests to be used on the data. McNemar's χ^2 tests for correlated groups (Maxwell, 1961, p. 26) were then calculated. Subsequently, however, in the absence of Professor Hawkins and in consultation with Dr. G.V. Kass of the same department, it was observed that the Sign test would give exact p values, for the sample size of the present study, where McNemar's test gave only approximations. The data was re-analysed using this test, which is also simpler to use since appropriate tables are available. Very few differences actually became apparent when results from McNemar's test and the Sign test were compared, only one border-line significant difference was found not to be significant on the Sign test result and was subsequently omitted from the discussion.

2. For the conditions which must be satisfied before parametric tests can be applied, see Siegel, 1956, p. 19.

The value of p was calculated for a two-tailed test, because the prediction was simply that the frequencies with which the variables occurred would be significantly different and the direction of these differences was not specified. Differences were accepted as significant if a p value of less than 0.05 was found, with the reservation that, since many tests were being carried out, there would be a chance that five per cent would show significant differences simply by definition of a significance level.

Apart from name and address, and the information in Section 6.2 above, Section II of the schedule dealt with the educational history, religion, occupation, arrests, changes of residence, medical history, family and childhood background, recreational interests and hobbies of the subjects. The results of the data collected in these areas are reported in Sections 6.3.1 to 6.3.8 below.

6.3.1 Educational History

A number of items were concerned with various aspects of the educational history of the subjects. The results showed that the educational history for the two groups was very similar, presumably partly due to the fact that the two groups were matched for the combined factors of education and age.

One item on education concerned the age on starting school. The results are shown in Table 6.3 and indicate close similarity between the groups. The oldest starting age among the controls was 11 years whereas two of the albinos were 14 years at the time of starting school. The fact that only 17 albinos and 19 controls started school at 6 to 7 years may be explained by the fact that

TABLE 6.3. AGE OF ALBINO AND CONTROL SUBJECTS ON STARTING SCHOOL

AGE (IN YEARS)	ALBINOS	CONTROLS
6 - 7	17	19
8 - 9	9	9
10 - 13	6	7
> 14	2	0
No education	1	0
Total	35	35

schooling is not compulsory in Soweto[5], so that the age of a child starting school depends on a variety of factors.

The subjects were also required to give information on the number of classes they had repeated during their school careers. The results of the responses to this item are recorded in Table 6.4. Again the two groups showed a similar pattern.

TABLE 6.4. NO. OF CLASSES REPEATED BY ALBINO AND CONTROL SUBJECTS

NO. OF REPEATS	ALBINOS	CONTROLS
None	9	10
One	17	18
Two	4	6
Three or more	2	1
No education	1	0
No information	2	0
Total	35	35

5. See page 39 of the present study.

They did however show tendencies to differ on the actual class repeated. The albino group repeated Std. I more frequently and the control group repeated Std. II more frequently. There were five albinos and eight controls who repeated Std. VI. This result could be a reflection of the education system in Soweto where there is keen competition for post primary school places, so that repeats in Std. VI may be for the purpose of obtaining sufficiently high marks to qualify for a place in the High School.

6.3.2 Religion

A religious affiliation was recorded for all but two of the albino subjects and one control subject. The majority belonged to the churches of the major denominations in Soweto. Almost 25 per cent, however, belonged to the various African Independent Churches, which have proliferated in Soweto over the years[6]. The religions of the two groups appear in Table 6.5.

TABLE 6.5. RELIGIOUS AFFILIATION OF ALBINO AND CONTROL SUBJECTS

RELIGION	ALBINOS	CONTROLS
Anglican	3	11
Roman Catholic	8	6
Dutch Reformed	7	2
Lutheran	3	2
Methodist	4	3
African Independent Churches	7	9
No religion	1	1
No information	2	1
Total	35	35

6. See page 44 of the present study.

6.3.3 Occupation

The occupation of the majority of subjects was 'scholar', so that not much information was collected as a result of this item. Several scholars had had temporary holiday jobs and two young albino brothers who had left school at an early age had sold newspapers for varying short periods of time.

6.3.4 Arrests

The majority of the subjects in both groups stated that they had never been arrested. A total of three albinos and four controls, however, admitted to having been arrested. Two of these albinos and one control were arrested for minor pass-book[7] offences. The remaining offences which caused arrests were: being in possession of a knife (an albino); opening the door of a moving train (a control); stealing washing from a store (a control); and pilfering cold drinks (a control).

6.3.5 Changes of Residence

The subjects were required to state how many times they had moved house since birth. The results indicated that there were 23 of the 35 matched pairs of subjects who had had changes of residence and one pair who had not changed. In the remaining 11 pairs there was one pair where the albino had changed and the control had not, but in ten pairs the control had changed and the albino had not, the difference between the two groups was therefore

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7. Every black individual in Soweto, who is over the age of 16 years, is required to carry a pass-book, or reference book, containing his/her identifying details, documents and permits.

significant at the five per cent level. The results of this section are reported in Table 6.6.

TABLE 6 6. CHANGES OF RESIDENCE AMONG ALBINOS AND CONTROLS : PAIRWISE COMPARISON (35 PAIRS)

CHANGES OF RESIDENCE	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p**
1 or more	[illegible]	1	1	10	11	0.02

* ++ present for albino and control
-- absent for both
+- present for albino, absent for control
-+ absent for albino, present for control.

** differences were accepted as significant if $p < 0.05$.

This finding is of interest since it may be concluded that the albinos, according to the information given by the subjects here, have had fewer changes of residence, and therefore possibly have had a more stable home environment than the controls.

6.3.6 Medical History

The item concerned with medical history elicited many responses from both groups, and the information on the matched pairs appears in Table 6.7. There were 28 pairs in which both members complained of problems and only one pair in which there were no problems. The albino subjects complained of a total of 67 and the controls of 42 medical problems. However of these 67 problems 29 were related to visual and skin problems, which are associated with the albinos' physical condition, the controls only complained of a total of nine problems of this nature. It is interesting that the majority of albinos complained of visual rather than dermatological problems

TABLE 6.7. MEDICAL PROBLEMS OF ALBINOS AND CONTROLS : PAIRWISE COMPARISON (35 PAIRS)

MEDICAL PROBLEMS	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
None	1	28	1	5	6	0.21
Visual	2	15	17	1	18	0.001
Skin	1	20	9	5	14	0.42
Accidents	5	17	10	3	13	0.09
Stab wounds	1	29	1	4	5	0.36
Tuberculosis	0	31	4	0	4	0.12
Hospitalization	4	18	7	6	13	1.00
Operations	0	30	2	3	5	1.00

* For explanatory footnote see Table 6.6, page 86.

and that when the results of the matched pairs were examined visual problems was the only variable on which a significant difference between the groups was shown. This situation might have been different if an older group had been selected as subjects, since albinos frequently develop skin cancer later in their lives[8]. If these two categories are excluded from the analysis of medical problems the albino and control group reported a similar number of problems (38 and 33 respectively) and there were no other significant differences between the two groups.

It is interesting also that four albino subjects had had tuberculosis whereas no control subjects reported having had this disease, this finding however needs a larger sample in order to confirm an association between albinism and tuberculosis. Again it is possible that if the albino is constantly trying to escape

8. See page 10 of the present study.

the sun he may remain longer indoors, where conditions are often stuffy and unhealthy and may make him susceptible to conditions such as tuberculosis.

6.3.7 Family Background

From the information given by the subjects on their family background the albino group did not show any significant difference in comparison with the control group. The data concerning this section are reflected in Table 6.8. The results indicated the high rate of family disorganization which is prevalent in Soweto[9] Almost one

TABLE 6.8. FAMILY BACKGROUND OF ALBINOS AND CONTROLS : PAIRWISE COMPARISON (35 PAIRS)

	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
Death of parent	1	20	7	7	14	1.00
Separated parents	1	24	4	6	10	0.74
Fatherless families	3	17	7	8	15	1.00
Illegitimate birth	0	31	0	4	4	0.12
Raised by relatives	1	29	4	1	5	0.36
Family position:						
First born	1	17	9	8	17	1.00
Second third	6	9	8	12	20	0.50
Fourth	4	18	8	5	13	0.58

* For explanatory footnote see Table 6.6, page 86.

third of the subjects in each group were living in fatherless families, or with female household heads, and only 17 of the 35 matched pairs claimed that fathers were present in the home. This again reflects the situation as it is in Soweto, where

9. See page 35 of the present study.

almost 25 per cent of families have female heads. There was a correspondingly high incidence of separated parents and families in which there had been the death of a parent, and there were no differences between the two groups on these variables.

The distribution in the two groups of family position of the subjects was again remarkably similar. It appears that many of the albino subjects came from large families and one might deduce from this observation that the condition does not seem to be a deterrent to child-bearing in the black community.

6.3.8 Recreational Interests

The major recreational pursuits of both groups involved sport, and as many of the albinos stated that they participated as did the controls. Attending film shows and reading were also interests common to both groups. Many hobbies were recorded from drawing, playwriting and chess to sewing and wire-cart making. Two particular interests of the albino group were church-attendance and music. There was a significant difference between the two groups for church-attending, but not for musical interest, as indicated on Table 6.9. This association between albinos and religious interests has been reported in other studies[10].

The information on the two groups regarding radio listening is shown on Table 6.9. Significantly more of the controls stated that they pursued this interest with friends. The albinos may be showing a tendency here toward some social isolation; on the other hand they may, in order to shelter from the sun, be staying in the house (where this interest is usually pursued) more frequently than nor-

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10. See page 24 of the present study.

TABLE 6.9. RECREATIONAL INTERESTS OF ALBINOS AND CONTROLS : PAIRWISE COMPARISON (T- PAIRS)

INTEREST	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++[#]	--	+-	-+	n	p*
Church-attending	3	13	16	3	19	0.004
Music	0	24	8	3	11	0.22
Radio-listening:						
Alone	5	14	11	5	16	0.21
With friends	6	15	2	12	14	0.01

* For explanatory footnote see Table 6.6, page 86.

mally pigmented youth would, and for this reason may not have friends with them so often.

6.4 Summary

In summary then the social profile of the young albino subjects in the present study in comparison with the controls may be outlined as follows:

(1) There were more males than females (the ratio being 3 : 2)[11]; the average age was seventeen years; they had had a mean number of eight years of schooling, with a range of none to eleven years. The control group presented a similar picture since they were matched, on these characteristics, to the albino group.

(2) The albinos had started school at approximately the same age as the controls, and had repeated as many years of schooling.

(3) They belonged to the same major church groups as the controls.

(4) They indicated a similar petty crime record to the controls.

(5) They stated that they had changed residence significantly less frequently than the controls.

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11. Similar ratios have been found in other studies, see page 23 of the present study.

(6) They had experienced more medical problems than the controls, but many of these problems were associated with their condition. On exclusion of the albinism-related medical problems they showed a similar number and pattern of problems to the control group.

(7) They showed a similar pattern of family disorganization to the control group, with as many parental deaths, separated parents and fatherless families as the controls.

(8) They stated that they participated in sporting activities, and had many hobbies, but the controls pursued their interest in radio listening with friends more frequently than the albinos did. The albinos on the other hand took a significantly greater interest in religious activities and church attendance.

6.5 Conclusion

The analysis of the data collected on Section I of the schedule was merely a 'fishing-expedition' to determine whether there were any major differences between the albino and control groups. On such an expedition one might expect to find 5 per cent of the differences to be significant. However of the 21 variables, which were unassociated with the matching criteria, and on which the Sign tests were calculated, one was found to show a significant difference between the groups with $p < 0.05$, and three with $p < 0.01$. Using Wilkinson's (1951) tables (on the probability of obtaining n or more significant statistics by chance in a group of N, where statistics are significant at the 5 per cent level) the likelihood of this event, i.e. four of 21 variables showing significant differences between two groups, happening by chance is only one in 100 times (or $p < 0.01$) so these differences were considered significant, they were used in the discussion and tentative conclusions were drawn.

The information collected from the responses to the items in Section I indicates that on most of the uncontrolled variables the albino subjects show a similar picture to the controls. The albinos

are therefore not very different from the normally pigmented young people of Soweto, as regards education, religion, criminal tendencies, or family background. They do, however, claim to have more medical problems (but these are generally related to their condition) as well as more stable homes, with less changes in residence, and more interest in church attendance than the control group. This information is of value as a background to the analysis of the adjustment and attitude items in Section II and III of the schedule.

CHAPTER 7

RESULTS OF SECTIONS II AND III OF THE SCHEDULE

7.1 Introduction

The results of Section I of the schedule as reported in the previous Chapter showed that there were no major differences between the albino and control group on the variables investigated. The analysis of Section II was therefore undertaken to determine whether albinism was associated with good or poor adjustment and whether any differences between the albino and control group might be related to the information obtained from Section I. The data collected by means of the items in Section III were then analysed to assess whether the attitudes towards albinism of the control group and the albino group differed in any way, and if there were differences, whether these could either be associated with any problems of adjustment that the albinos might have, or linked with the minor differences which became apparent on the assessment of the data from Section I.

7.2 Results of Section II on Adjustment

Two steps were involved in the analysis of the data obtained from Section II of the schedule. Firstly, an item analysis was undertaken to assess the value of the items. Secondly, the two groups were compared on the retained items to see whether any difference in patterns of behaviour emerged, and whether albinism could be associated with problems in any particular area.

7.2.1 Results of Item Analysis

The total number of items in Section II of the schedule was thirty-two. These items were analysed using Likert's (1932) method of

summated ratings[1]. A Discriminatory Power (D.P.) value was found for each item and if the D.P. value reached the required level of significance ($p < 0.01$) then the item was considered useful and retained in the schedule. The level of significance tables for two-tailed tests were used since the hypothesis for the present study did 'not indicate the predicted direction of the difference' (Siegel, 1956, p. 13) between the experimental and control groups.

As a result of the item analysis twenty items were retained and twelve were rejected. These items, their D.P. and p values are shown in Table 7.1.

It seems that many of the rejected items were not explicitly worded and were of too vague and general a nature to be of value. For example the four items concerning relationships with parents and siblings were all rejected by the item analysis. Other items were too easy so that the majority of both groups responded in one direction, either positively or negatively, and the item was not discriminating. Examples of such items were 'Do you sleep well at night?' and 'Do you cry often?' There was one borderline item (No. 30 in Table 7.1) but since the accepted statistical level was ≥ 2.50, this too was rejected.

7.2.2 Results on Retained Items

The responses to the retained items were scored and t values computed to bring out any differences between the albino and control groups. The t test for matched samples (McCall, 1970, p. 188) was used for this purpose, and a 5 per cent level of significance was selected.

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1. See page 62 of the present study.

TABLE 7.1. SECTION II : RESULTS OF ITEM ANALYSIS

NO.	ITEM	D.P. VALUE	p
16.	Are you satisfied with what you do during the day	2.93	< 0.01*
17.	Do you day-dream often	8.35	< 0.005*
18.	Have you any habit you think is unusual	1.98	> 0.05
19.	Are you happy most of the time	3.53	< 0.01*
20.	Do you often have sweating palms	2.64	< 0.01*
21.	Are you ashamed because of your physical appearance	2.50	< 0.01*
22.	Do you often blink	2.75	< 0.01*
23.	Do you find it difficult to speak in a group of people	3.87	< 0.01*
24.	Do you sleep well at night	0.86	> 0.20
25.	Do you often bite your nails	0.35	> 0.20
26.	Do you often feel like running away from home	3.82	< 0.01*
27.	Do you feel happy with your brothers	0.47	> 0.20
28.	Do you cry often	1.98	> 0.05
29.	Do you cry when your heart is sore	2.97	< 0.01*
30.	Do you feel well and strong most of the time	2.47	> 0.02
31.	Are you unhappy with your sisters	1.98	> 0.05
32.	Do you feel wanted and needed by your family	2.05	> 0.05
33.	Do you make plenty of friends	3.87	< 0.01*
34.	Do you often get anxious	2.28	> 0.05
35.	Do you think others treat you unfairly	5.50	< 0.01*
36.	Do you often get sick so that you have to stay away from school/work	1.94	> 0.05
37.	Is there one sickness that troubles you most	2.30	> 0.02
38.	Have your relations with your father usually been pleasant	2.31	> 0.02
39.	Do you often get headaches	3.12	< 0.01*
40.	Do your relatives dislike you	2.77	< 0.01*
41.	Are other people to blame for any of your present troubles	6.42	< 0.005*
42.	Have you always been on good terms with your mother	1.47	> 0.10
43.	Do you often get angry when talking to people	4.01	< 0.01*
44.	Do you usually speak to strangers on the bus or train	3.18	< 0.01*
45.	Do you feel you have any special handicaps that other people don't have	3.33	< 0.01*
46.	Do you feel that other people are always looking at you	10.48	< 0.005*
47.	Do you feel your friends have a happier home life than you	3.10	< 0.01*
48.	What troubles you most often	2.94	< 0.01*

* Retained items.

The two independent clinical psychologists assessed the responses to the 'Whys' appended to certain items in terms of adjustment, and further results were obtained from these assessments. The results are reported in six sections, the experimental and control group were compared on: overall scores, sub-group scores, scores of males and females, sub-scale scores, item differences and on the basis of the scores obtained from the assessments made by the clinical psychologists.

7.2.2.1 Comparison of Albino and Control Groups on Overall Scores

There were a total of 700 responses given by each group to the twenty items in Section II of the schedule. Included in this number were 56 'Don't know' responses by the albinos and 27 'Don't know' responses by the controls. In neither group was 'no information' recorded for any item in this Section.

The results of the comparison of the two groups on mean overall scores on the twenty adjustment items are shown on Table 7.2.

TABLE 7.2. COMPARISON OF ALBINO AND CONTROL SUBJECTS ON MEAN TOTAL SCORES FOR ADJUSTMENT*

	ALBINOS (N = 35)	CONTROLS (N = 35)	t	p
Mean Score	44.06	44.08	0.02	> 0.90
Standard deviation	8.08	8.31		

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

The findings here show that there was no significant difference between the mean total score of the subjects in the albino group and that of the control subjects as regards their adjustment. Within

the limitations of this test then, it may be stated that albinism is not associated with good or poor adjustment according to the data obtained from the present study. The albinos appeared to be as generally well-adjusted, or poorly adjusted, as the controls and further detailed analysis of the responses of the two groups was required if any problematic features of their adjustment were to be determined.

7.2.2.2 Comparison between Sub-groups

Since there was no difference at the level of the total scores of the two groups, a secondary analysis was carried out. This analysis was an additional precaution to assess whether there were any differences at any level which would not be reflected in the total scores, but would be indicated by studies of sub-group scores.

The two groups had been matched on certain criteria[2] among which was sub-group. These were the Higher Primary School, High School and Drop-out subjects. The scores for these sub-groups were separated and compared[3] and the results are shown on Table 7.3.

Again there were no significant differences between the scores on adjustment of the albinos and controls in the Higher Primary School, High School, or in the Drop-out sub-group. The results of the subjects in the two groups showed a similar pattern. The High School subjects in both groups showed the highest scores, indicating good adjustment, and the Drop-out subjects in both groups showed the lowest scores indicating poor adjustment.

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2. See page 51 of the present study.
3. Statistical calculations involved the use of t tests for matched samples (McCall, 1970, p. 188). The analysis of variance might have been a superior statistical method, but since only a secondary analysis was involved the t test was considered sufficient.

TABLE 7.3. COMPARISON OF ALBINO AND CONTROL SUB-GROUPS ON MEAN SCORES FOR ADJUSTMENT*

SUB-GROUP	N	ALBINOS MEAN	CONTROLS MEAN	t	p
Higher Primary School	14	44.53	43.57	0.45	> 0.50
High School	10	47.80	49.80	0.70	> 0.20
Drop-out	11	39.73	39.54	0.05	> 0.90
Total	35				

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

7.2.2.3 Comparison between Scores of Males and Females

A further secondary analysis was carried out for the purposes of ascertaining whether or not there were differences between the adjustment scores of the males and females in the two groups. This analysis was not attached to the main hypothesis of the study, but intended to give further relevant information. The results of the calculations are shown in Table 7.4.

TABLE 7.4. COMPARISON OF ALBINO AND CONTROL MALES AND FEMALES ON MEAN ADJUSTMENT SCORES*

	N	ALBINOS MEAN	CONTROLS MEAN	t	p
Males	21	44.62	46.67	1.00	> 0.20
Females	14	43.36	40.21	0.91	> 0.20

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

The control males showed slightly higher scores for adjustment than the albino males, but this difference was not statistically significant. The albino females, on the other hand, scored slightly higher than the control females, suggesting a better adjustment, but this again was not a statistically significant finding.

As a further 'fishing expedition' and to obtain information regarding any other differences that might be evading analysis, the results of the males and females in the sub-groups were investigated. These results are reported in Table 7.5.

TABLE 7.5. COMPARISON OF ALBINO AND CONTROL SUB-GROUP MALES' AND FEMALES' MEAN SCORES

SUB-GROUP	MALES			FEMALES		
	N	ALBINO	CONTROL	N	ALBINO	CONTROL
Higher Primary School	7	41.43	48.28	7	43.43	38.85
High School	8	50.00	49.00	2	39.00	53.00
Drop-outs	6	35.33	41.67	5	45.00	37.00
Total	21			14		

Because the numbers of subjects in the sub-groups were very small, these results were not submitted to statistical analysis. Impressions only, rather than conclusions, can be obtained from the data given here. It is nevertheless interesting that in the Higher Primary School group and in the Drop-out group male albinos scored lower than male controls, but female albinos scored higher than female controls. The impression given by these results concerns the tendency for the albino males to be worse adjusted than the controls, but the albino females to be better adjusted than the control females. This information is of value in indicating a

direction for future research, and it would be interesting to confirm this finding with a larger sample.

7.2.2.4 Results on Sub-scales

The sub-scales, i.e. Emotional, Interpersonal and Physical, were rather depleted after the rejection of the non-discriminatory items. There were seven items retained on the Emotional sub-scale, ten items on the Interpersonal and three on the Physical. Because of this imbalance it was decided that comparisons between totals of the two groups on the sub-scales would not provide a valid indicator of where the major problems lay. There was also the possibility that the selection of items for each sub-scale was rather arbitrary and that several items could have been classified as both interpersonal and emotional by content, and others with a psychosomatic slant as either emotional or physical. For these reasons analysis in this direction was discontinued.

7.2.2.5 Comparisons on Individual Items

The mean scores of the subjects in the two groups were then studied item by item and comparisons were made between the albino and control group on each of the twenty items.

There were fourteen items that showed no differences between the albino and control groups. Neither group claimed to have any specific handicaps that others did not have. There was no difference in the number of subjects in each group who claimed that others were looking at them (which was surprising, and possibly unrealistic on the part of the albinos). The two groups showed similar trends regarding their claims to having plenty of friends, and on the items concerned with whether others treated them unfairly or were

to blame for their troubles. The majority of the subjects in both groups claimed to be happy at home, were satisfied with their everyday life and did not claim that their friends had happier homes than they did.

There were, however, six items on which the differences between the groups were statistically significant. The results on these items are shown in Table 7.6.

TABLE 7.6. SECTION II ITEMS WHICH SHOWED SIGNIFICANT DIFFERENCES BETWEEN THE MEANS OF THE ALBINO AND CONTROL GROUPS*

ITEM	ALBINO	CONTROL	t	p
20. Sweating palms	1.60	2.09	2.19	< 0.05
21. Ashamed of appearance	2.45	1.86	3.21	< 0.01
22. Blinks often	1.66	2.47	6.73	< 0.001
39. Headaches	1.74	2.23	2.40	< 0.05
44. Speaking to strangers	2.17	1.69	2.15	< 0.05
48. Troubles	1.37	1.94	2.62	< 0.02

* Where a score of 3 indicates good adjustment and 1 poor adjustment.

These six items could almost constitute a sub-scale on the physical aspects of adjustment. At least three, and possibly as many as five, of the items could be related to physical or at least psychosomatic problems. The albino group claimed to have more headaches, blink more often (as might be expected from the photophobia commonly suffered by albinos), and have sweating palms more often, than the control group. The headaches and sweating palms might be caused partially by the condition of albinism, but they could also be said to be psychosomatic symptoms indicating deep seated problems. The number of 'troubles' reported by the albino group was also significantly higher than the number reported by the control group. Again the albino responses included many

'troubles' which were related to health complaints.

The results on item 21 (see Table 7.6) are worthy of comment, since they are rather unexpected. The albinos showed a significantly more positive response than the control group towards their own appearance. This result suggests that the albinos may have a better self-concept and possible reasons for this finding will be discussed in Chapter 10. Item 44 showed that significantly more albinos than controls were willing to speak to strangers and this could be related to the albinos' satisfaction with his own appearance and consequently his increased self-confidence.

In conclusion then, the results of the comparison of item means showed that on the fourteen items the groups did not differ. On four items, which could be said to be related to physical problems, the albino group scored significantly lower, showing a poor adjustment in these areas. On a further two items, which were possibly related to self-concept, the albinos scored higher showing a better adjustment than the controls in this area.

7.2.2.6 Comparisons based on the Clinical Psychologists' Assessments

Two clinical psychologists (one of whom was registered and the other newly qualified and seeking registration, and both of whom were females) were asked to act as judges and to assess, independently, the responses to the 'Whys' that were appended to certain items in the schedule. They were required to rate the responses according to the predetermined methods. The identifying details of each subject, as well as their status as either albino or control, was removed from the schedules and replaced by code numbers, so that the judges should carry out a 'blind' analysis.

The scores of the two judges were totalled separately for each subject and Spearman's rank correlation coefficient (for the method used see Siegel, 1956, p. 202) was calculated to measure the correlation between the two sets of scores. The correlation coefficient on the judges' scores for the albino group was 0.58 and for the control group 0.78. Using a one-tailed test of significance (since there was a predicted direction i.e. it was expected that there would be an association between the scores of the judges) these values were significant at the $p < 0.01$ level. It could therefore be concluded that the judges' scores were associated. Each subject was then given a new score, which was the mean of the score given by the two judges. The results of the subsequent analysis of these scores are shown in Table 7.7.

TABLE 7.7. COMPARISON OF ALBINO AND CONTROL SUBJECTS ON THE CLINICAL PSYCHOLOGISTS' ASSESSMENTS

	N	MEAN SCORES*		t	p
		ALBINO	CONTROL		
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 a score of 7 indicates very good adjustment and 1 poor adjustment.

According to these results there was a significant difference between the two groups. The clinical psychologists judged the albinos as better adjusted than the controls. On examination of the figures for males and females it became apparent that it was the females who were causing the differences between the two groups. The female albinos were judged better adjusted (and this was

significant at the $p < 0.01$ level) than female controls, whereas the males in the two groups showed no difference. This finding is interesting since it bears out the impressionistic evidence gained from the analysis of the scores of males and females in the sub-groups[4].

7.3 Results of Section III on Attitudes

Again two stages were involved in the assessment and analysis of the results on Section III of the schedule. This Section contained items concerned with attitudes towards albinism of both the albino and control groups, as well as some open-ended items on the problems of albinos, on social work and on the purpose of the interview. The first stage consisted of two steps: the formulation of an attitude scale, with some internal consistency, by means of Likert's technique[5], and then the analysing of the results of the responses to the items retained on the scale and the comparing of the two groups. The second stage was the calculation of frequencies for the responses on the open-ended items and the comparing of the groups by means of the relevant statistical tests (the Sign test, (Connover, 1971, p. 127) was used)[6].

7.3.1 Results of Item Analysis : Retained and Rejected Attitude Items

The fourteen items measuring attitudes toward albinism, in Section III, were treated in the same way as the adjustment items in Section II. After item analysis four items were rejected, since

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4. See page 99 of the present study.
5. See page 62 of the present study.
6. See page 81 of the present study.

their Discriminatory Power values did not reach the required level of significance ($p < 0.01$), and ten items were retained as valuable items. The details regarding these items are given in Table 7.8.

TABLE 7.8. SECTION III : RESULTS OF ITEM ANALYSIS

NO.	ITEM	D.P. VALUE	p
50.	Do you think albinos should have certain jobs	1.91	> 0.05
51.	Do you think albinos have difficulty getting jobs	4.12	< 0.01*
52.	Would you work in the same room as an albino	4.89	< 0.01*
54.	How clever do you think albinos are	1.30	> 0.20
55.	Can albinos live like everyone else	2.43	> 0.02
56.	Do you think they have specific personal characteristics	3.82	< 0.01*
57.	Do you think albinos should marry	1.46	> 0.10
58.	Do you think blacks should marry albinos	2.70	< 0.01*
59.	Would you let your child marry an albino	5.76	< 0.01*
62.	How do you feel about having albino friends	9.22	< 0.005*
63.	Would you eat from the same pot as an albino	7.42	< 0.005*
64.	Would you sit next to an albino on the bus	3.69	< 0.01*
65.	What kind of skin problems do you think they have	3.07	< 0.01*
66.	What do you think happens to albinos at the end of their lives	2.61	< 0.01*

* Retained items.

The four rejected items were probably either too easy or too difficult for the subjects, so that the majority responded in one direction, either positively or negatively, and the items were of no discriminatory value. For example most subjects in both groups responded positively to the item concerning whether albinos should

marry, so that this item had a low D.P. value and was rejected.

The subjects were scored by the writer on the ten items that remained to constitute the attitude scale.

7.3.2 Results on Retained Attitude Items

The results on the retained items concerning the attitudes towards albinism of the albino and control group are reported here in two sections : comparisons between the groups on total scores and comparison between the groups on individual items. The statistical analysis of the data included calculation of the means and the difference between the means of the two groups for the total scores and for the scores for each item. The significance of the difference between the means of the totals, and of each item, was determined by computing t values, using the appropriate test for matched samples (McCall, 1971, p. 188) and finding the level of significance (p value).

7.3.2.1 Comparison of Albino and Control Groups on Total Scores

The results of the comparison of the two groups on their total scores for the attitude scale in Section III of the schedule are shown on Table 7.9.

On the total mean score there was no significant difference between the albino and control groups. The two groups showed similar reasonably positive attitudes towards albinism according to the results from the limited information obtained on the ten items from the schedule Section III.

In order to gain further details on this finding, a secondary analysis was undertaken and the scores of the males and females were calculated separately and analysed. The results of these calculations

TABLE 7.9. COMPARISON OF MEAN TOTAL SCORES FOR ATTITUDES TOWARDS ALBINISM OF ALBINO AND CONTROL SUBJECTS*

	N	ALBINOS	CONTROLS	t	p
Males	21	25.67	23.09	2.07	< 0.05
Females	14	23.14	26.21	1.93	> 0.05
Total	35	24.66	24.34	0.29	> 0.20

* Where a score of 30 indicates a positive attitude towards albinism and 10 indicates a negative attitude towards albinism.

are also shown on Table 7.9. There was a statistically significant difference between the males in the albino group and the males in the control groups. The control males were significantly less positive towards albinism than the albino males. This finding was of particular interest when considered in conjunction with the impressions gained from the findings on the adjustment section of the schedule viz. that the albino males were frequently found to be less well adjusted in comparison with the control males[7]. These results suggested that the albino males' adjustment problems might be partly due to the attitudes of the young black males, who did not show such positive attitudes towards the albino as the albinos showed towards themselves.

The female scores, on the other hand, did not show any difference between the groups. The control females showed a tendency to be more positive towards albinism than the albino female group, but the difference was not significant. This 'negative' information was interesting, since it suggested that the albino and control females

7. See page 99 of the present study.

showed the same level of acceptance of albinism. The albino females tended to show a better adjustment than the control females[8] and this might partly be caused by the positive attitudes of black females towards albinos.

7.3.2.2 Comparison of Albino and Control Groups on Individual Items

The results of the albino and control group on each of the ten items on the attitude scale in Section III are shown in Table 7.10.

There was very little difference between the scores of the albino and control group on the attitude items concerned with social distance (items 2,3,5,6,7,8 in Table 7.10). The attitude of the control group towards albinos was generally positive. The majority agreed that there should be marriage between normally pigmented and albino people and that they would allow their children to marry albinos. They also showed positive attitudes towards travelling, working, friendship and eating with albinos (listed in this order of priority). The albinos' attitudes, which were similarly positive, showed mean item scores which were ordered as follows : travelling, then eating and working, and lastly friendship with other albinos.

There were two attitude items which showed significant differences. Item 1 was concerned with the difficulty that albinos might experience in obtaining employment. The majority of the albino group considered that it would be difficult for albinos to get work, but significantly less of the controls responded that the albinos would have this difficulty. Very few of the subjects in the present study had ever tried to obtain employment, but the albinos seem to be anticipating that this will be a serious problem for them.

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8. See pages 99 and 103 of the present study.

TABLE 7.10. COMPARISON OF ALBINO AND CONTROL SUBJECTS ON ATTITUDE ITEMS

NO.	ITEM	ALBINOS MEAN	CONTROLS MEAN	t	p
1.	Do you think albinos have difficulty getting jobs	1.69	2.31	3.19	< 0.01
2.	Would you work in the same room as an albino	2.57	2.57	0.00	
3.	Do you think they have specific personal characteristics	2.23	2.31	0.36	> 0.20
4.	Do you think blacks should marry albinos	2.85	2.83	0.83	> 0.20
5.	Would you let your child marry an albino	2.69	2.74	0.36	> 0.20
6.	How do you feel about having albino friends	2.34	2.43	0.39	> 0.20
7.	Would you eat from the same pot as an albino	2.66	2.34	1.45	> 0.10
8.	Would you sit next to an albino on the bus	2.77	2.74	0.17	> 0.20
9.	Do their skin problems affect you in any way	2.57	2.23	1.79	> 0.05
10.	What do you think happens to albinos at the end of their lives	2.29	1.83	2.28	< 0.05

(Where 3 indicates a positive attitude toward albinism and 1 a negative attitude).

The most interesting result in this section came in response to item 10 and here again there was a significant difference between the albino and control group. The subjects were asked 'What do you think happens to albinos at the end of their lives', (the reason for this item was the writer's experience concerning the myths that surround the death of the albino). The results of a frequency count of the responses to this item are shown in Table 7.11.

TABLE 7.11. ATTITUDES OF ALBINOS AND CONTROLS TOWARDS THE DEATH OF ALBINOS : PAIRWISE COMPARISON (35 PAIRS)

RESPONSE	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
Not sure	4	20	7	4	11	0.54
They die	4	16	9	6	15	0.60
They die, 'but I've never heard of an albino's death'	1	28	6	0	6	0.03
They vanish	0	20	0	15	15	< 0.001
No response	0	30	4	1	5	0.36

* For explanatory footnote see Table 6.6, page 86.

For the control group the most striking result was shown by the 15 subjects who responded that albinos vanish at the end of their lives, or die in mysterious circumstances. Two examples are typical of the responses obtained on this item : 'I always hear people say albinos are never buried, they walk away and disappear to die far from home'; 'They fall ill, then recover quickly, and after this disappear to die away from other people. Whether death follows or not is still a mystery'.

A total of 16 of the albino group said that they had heard the rumour, but either did not believe it or were not sure about it.

The rumour appears to be circulated in two forms, either 'I've never heard of or seen an albino's death, therefore I wonder what happens to albinos, or 'Albinos go far away from home and die, or disappear, or vanish, so that no-one can trace them and they cannot be buried'. The majority of albinos expressed the rumour in the first form and the majority of controls in the second form. Eleven of the albinos stated that they were not sure what would happen at the end of their lives. They also appeared to have ambivalent feelings; for example the response of a Higher Primary School albino subject was 'I haven't heard that an albino has died. I think they die. But other people say they vanish, I don't believe in that'.

Among both groups there were only 23 subjects (13 albinos and 10 controls) who responded definitely that albinos die at the end of their lives. Myths and rumours concerning the death of albinos are causing confusion in the minds of the remaining two thirds (47 out of 70) of the subjects.

In conclusion then, studies of the results on the items on attitudes show that although these are generally positive, there is at least one area in which the albino is viewed as very different; this area is concerned with the prevailing belief that mystery surrounds the albino's death.

7.3.3 Results on Open-ended Items

Various open-ended items were inserted in Section III of the schedule in order to obtain further data of a descriptive nature and to assist in the interpretation of the findings. These items covered general aspects of albinism, impressions on social work and one item to find out what the subjects considered was the purpose of the interview. The results of the responses on these

items will be reported below.

7.3.3.1 Albinism

Five open-ended items were included in order to assess the understanding of albinism by the albino and control group. These items related to the problems, causes and inheritance of albinism.

The first item, which was concerned with the problems of albinos, gave results which are shown in Table 7.12.

TABLE 7.12. ALBINOS' AND CONTROLS' PERCEPTION OF THE PROBLEMS OF ALBINOS : PAIRWISE COMPARISON (35 PAIRS)

PROBLEM	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
Skin problems	16	0	15	4	19	0.02
Eye problems	16	2	15	2	17	0.002
Skin and eye problems	8	4	21	2	23	< 0.001
Psychosocial problems	0	28	1	6	7	0.12

* For explanatory footnote see Table 6.6, page 86.

In both groups the majority expressed the problems of the albinos in terms of the physical condition. Although there were significant differences between the groups, as might have been expected since the albinos have more insight into their own condition, nevertheless the control group subjects showed a certain understanding of the physical problems associated with albinism.

The psychosocial problems mentioned were interesting. The one albino response in this category was 'Lack of love and tender care from parents leads to skin and eye problems'. Examples of the controls' responses are worth reporting here: '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 and don't wash'; 'They are never relaxed in company'; 'They are different from us in colour, this may be a great problem for them'. Fourteen per cent of the control group then considered that the albinos' problems might not be purely physical, but might be of a psychosocial nature.

The second general item on albinism concerned the etiology of albinism, and the responses obtained on this item are shown in Table 7.13.

TABLE 7.13. THE ALBINOS' AND CONTROLS' PERCEPTION OF THE CAUSES OF ALBINISM : PAIRWISE COMPARISON (35 PAIRS)

RESPONSE	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
A gift from God	1	29	3	2	5	1.00
A punishment from God	0	31	4	0	4	0.12
A creation by God	0	30	4	1	5	0.36
Genetic reasons	0	32	2	1	3	1.00
Parents did not eat the right food	0	31	0	2	2	0.50
Other†	0	33	1	1	2	1.00
Don't know	13	5	4	13	17	0.05
No response	0	31	3	1	4	0.62

* For explanatory footnote see Table 6.6, page 86.

† For explanation see text.

The albino group gave more information than the controls on this item, and the only outstanding difference between the groups is shown on the 'Don't know' responses; there were 13 pairs in which the control did not know the cause of albinism and only four pairs

where the albino did not know the cause. There were also 13 pairs which were tied, and neither albino nor control knew the cause. Nearly 33 per cent (11 subjects) of the albino group thought albinism was due to divine intervention. Seven subjects considered this intervention to be in the form of a gift, four that it was retribution in the form of a punishment for 'laughing at albinos', 'chasing them' or 'being afraid of them'. The 'other' category in Table 7.13 consisted of an albino's response: 'Something went wrong during the pregnancy that produced an albino infant', and a controls's response: 'Albinism might be caused by the mother's use of bleaching creams'.

The third item on albinism required responses from the subjects on the colour of the children of albinos. This item was included to obtain some information on whether or not the subjects had observed the pattern of inheritance of albinism. Table 7.14 shows the results of the data collected.

TABLE 7.14. ALBINOS' AND CONTROLS' RESPONSES CONCERNING THE COLOUR OF THE CHILDREN OF ALBINOS : PAIRWISE COMPARISON (35 PAIRS)

RESPONSE	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
Black	3	16	5	11	16	0.21
Albino	0	27	4	4	8	1.00
Albino or Black	3	20	4	8	12	0.38
Depends on parents' genes	1	33	0	1	1	
Other†	0	32	2	1	3	1.00
Don't know	0	24	9	2	11	0.06
No response	0	30	4	1	5	0.37

* For explanatory footnote see Table 6.6, page 86.

† For explanation see text.

The chance of an albino producing an albino child in this population is about one in 30, so that 29 out of 30 times the child of an albino will be black. There were three pairs in which both members stated that the children would be black, in five pairs the albino observed the same and in 11 pairs the control had observed this situation. There was one significant difference between the groups and that again resulted from the 'Don't know' responses. Nine albinos, which composed about 25 per cent of the group, did not know what colour their children would be, whereas only two controls or 6 per cent of that group were uncertain. Among the 'other' responses one albino and one control stated that if one parent were albino and the other black the children would be black, whereas if both parents were albinos the children would be albinos (this is true only where the parents both have the same type of albinism[9]), and another albino subject responded with 'If an albino marries a black the children will be black, but I have never seen the children of two albinos'.

The results of this item together with the previous one indicate that there is very little understanding of the genetics and etiology of albinism.

A fourth item was included in order to elicit information concerning tribal beliefs relating to marriage and contact with albinos. The majority of subjects responded that there was no tribal custom governing behaviour in this respect.

The final item was a general one requesting further information on albinism. There were only four responses from the albinos viz.:

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9. See page 8 of the present study.

'Albinos are people like others, except for skin and eye diseases'; 'I would like to know why albinos remain of average intelligence? Why don't we have albino academics? Is it because of their skin colour or what?'; 'I suggest albinos should try to get themselves well educated, so as to be socially acceptable and also be able to get good jobs, well paid, etc.'; 'I saw an albino in the scout team. This proves that albinos are normal, and can join in activities like blacks'. Seven controls contributed information on this item: two stated they had good friends who were albinos; two that albinos are very kind people; two commented further on physical problems and one said 'Albinos, apart from blinking a lot and peeling of skin, are people just like any normal black'.

These open-ended items gave additional information of a descriptive nature to complement the statistical results. In summary they indicated: that in the view of the subjects albinism was associated with some specific physical problems; that there was much ignorance concerning the causes and inheritance of albinism; that there were no commonly known tribal beliefs relevant to marriage or contact with albinos; and that albinos are considered to be 'normal' people, apart from their physical problems.

7.3.3.2 On Social Work

In order to make some assessment of the subjects' knowledge concerning social work and the extent of the need for social work service, two items were inserted towards the end of the schedule.

The first of these items was 'Have you ever had contact with or assistance from social workers?' The double barrelled nature of this item might have made it confusing, but nevertheless the results indicated the limited exposure to social work that the

'Albinos are people like others, except for skin and eye diseases'; 'I would like to know why albinos remain of average intelligence? Why don't we have albino academics? Is it because of their skin colour or what?'; 'I suggest albinos should try to get themselves well educated, so as to be socially acceptable and also be able to get good jobs, well paid, etc.'; 'I saw an albino in the scout team. This proves that albinos are normal, and can join in activities like blacks'. Seven controls contributed information on this item: two stated they had good friends who were albinos; two that albinos are very kind people; two commented further on physical problems and one said 'Albinos, apart from blinking a lot and peeling of skin, are people just like any normal black'.

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two groups had experienced. Among the subjects 87 per cent of the controls and 54 per cent of the albinos had had no contact with social workers. A further 42 per cent of the albinos had had contact with the writer (and this constituted one of the reasons for employing a black interviewer who was new to the situation, to conduct the interviews). Excluding these contacts then, 87 per cent of the controls and 96 per cent of the albinos had had no first-hand knowledge of social workers.

Nevertheless much interesting data was collected as a result of the next item. This item asked 'Do you think a social worker can help you with your problems?', and required a dichotomous response, with a 'Why' appended. The interviewer was instructed to probe and a great deal of information was elicited, as is shown in Tables 7.15 and 7.16.

TABLE 7.15. ALBINO AND CONTROL SUBJECTS' PERCEPTION OF WHETHER THE SOCIAL WORKER CAN HELP

RESPONSE	ALBINOS	CONTROLS
Yes	27	27
No	1	1
Don't know	5	7
No response	2	0
Total	35	35

The majority of subjects in both groups, although they had not had much contact with social workers, stated that the social worker could help. The 'Why' attached to the item yielded further information relating to the subjects' concepts of the role of the social worker and some of their expectations of social work.

TABLE 7.16. ALBINOS' AND CONTROLS' PERCEPTION OF HOW THE SOCIAL WORKER CAN HELP : PAIRWISE COMPARISON (35 PAIRS)

RESPONSE	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
Counselling/ advice giving	0	21	9	5	14	0.42
Material assistance	1	17	4	13	17	0.05
Counselling and material assistance	0	26	3	6	9	0.50
Other†	0	28	6	1	7	0.12
Don't know	0	19	8	8	16	1.00
No response	0	30	4	1	5	0.37

* For explanatory footnote see Table 6.6, page 86.

† For explanation see text.

The responses in the category on counselling and/or advice-giving included counselling in the areas of general, domestic, physical, employment, youth, career and relationship problems. The material assistance category included general or unspecified aid, as well as assistance with finance, bursaries and loans, books, food parcels and clothing, and the vague responses concerning helping the needy, the aged, the poor and orphans. The 'other' category showed six responses by the albinos who indicated that the social worker could assist with advice concerning skin care and could supply special cream. These responses were the direct result of the contacts between these subjects and the writer prior to the present study.

There was a significant difference between the two groups concerning the social worker as provider of material assistance. More subjects in the control group responded that the social worker could help in this way. Whether they were indicating their own feelings of need in this area, or whether they were indicating

the needs of their people, cannot be clarified with the limited information available.

Considering the traditional role of the social worker as provider of poor relief, it is interesting that so many subjects in the sample indicated an awareness of the counselling function of the social worker.

In summary the results on these two items on social work give information on the situation as the subjects see it in Soweto and show that there is very little contact with social workers. Nevertheless the responses also show that there appears to be a general feeling that social workers could help in many different ways, through their two broad roles as counsellor and environmental manager. A need for establishing contact with social workers is being expressed by the sample subjects, and, if the sample is representative of the public at all, their responses indicate that the potential for social work service in the Soweto commun'ty is tremendous.

7.3.3.3 On the Purpose of the Interview

The final item was included in the schedule to assess whether or not the subjects had understood the purpose of the research. If they indicated understanding it could, to a certain extent, be assumed that there was some validity in their responses. The item was 'Why do you think I have asked you these questions?', and the subjects had been informed, at the beginning of the interview, of the purpose and nature of the present study. The responses to this item are shown in Table 7.17.

It appears that the majority of the subjects understood, to a certain extent, the purpose of the research and in addition showed

TABLE 7.17. ALBINOS' AND CONTROLS' PERCEPTION OF THE PURPOSE OF THE INTERVIEW : PAIRWISE COMPARISON (35 PAIRS)

RESPONSE	TIED PAIRS		PAIRS SHOWING DIFFERENCES			
	++*	--	+-	-+	n	p*
To understand me and my problems	5	20	4	6	10	0.74
To understand and help me	1	20	13	1	14	0.001
To understand albinos	3	18	5	9	14	0.42
To understand me and the problems of youth	0	31	0	4	4	0.12
No response	0	25	4	6	10	0.74

* For explanatory footnote see Table 6.6, page 86.

some insight into the three-fold aim, i.e. the understanding of the individual subjects, the understanding of albinos and their problems, and the assessment in terms of a suitable helping response. The groups differed significantly as regards the help they expected as a result of the study. There were 13 pairs where the albino stated, and only one pair where the control stated that the purpose of the study was 'to understand and help me'. These responses were generally realistic and showed an accurate assessment of the situation. A contributing factor, however, might have been the contact the albinos had had with the writer, as social worker and researcher, prior to their participation in the present study.

7.4 Interviewer's Comments

The interviewer was required to write her comments on the progress of the interview and on any difficulties encountered. This information was requested in an effort to make some assessment of the reliability of the study, since it might be assumed that good

rapport and smooth interviewing would contribute to more reliable responses on the part of the subjects.

The interviewer stated that with 26 subjects in each group the interviews proceeded smoothly. She commented at greater length on the interviews with the albino subjects and noted that several were very shy and did not look directly at the interviewer. A few albinos had habits that were observed in the interview, for example one subject 'blocked her mouth by cupping her hands and spoke very slowly', another 'had his head bowed all the time', a third 'kept on clasping and brushing his hands toge er', a fourth 'kept on brushing his nose'. There were two albino subjects with whom the interviewer experienced particular difficulty, one was crying throughout the interview and the other was aggressive and repeatedly cross-questioned the interviewer.

The interviews with the control group seem to have been easier on the whole and no comments were made on two schedules. There was some difficulty with a few of these interviews, one subject was 'too absent minded', another 'talked with difficulty, obviously did not know much about albinism', a third subject was tearful when discussing the forced separation from her twin brother. Generally, however, the interviews in both groups were better and elicited more information from the older groups than from the younger Higher Primary School children. The interviewer's comments did not indicate any general problems specific to the interviewing of either the albino or control group.

7.5 Summary of Results

7.5.1 Section II on Adjustment

The study showed that:

(1) There was no significant difference between the mean scores for adjustment of the albino and the control group.

(2) There was no significant difference between adjustment scores of the two groups at any level, Higher Primary, High School or Drop-out.

(3) There was no significant difference between the total mean scores for the albino and control females, or between the albino and control males. Differences, however, appeared to be suggested in an investigation of the sub-group scores. The scores of the control males in the Primary School and in the Drop-out group showed a better adjustment level than the scores for the albino males. The analysis of the female scores however suggested that the albino females showed a better adjustment than the controls at Primary School level and again in the Drop-out group. These results were impressionistic only and require further investigation.

(4) There were significant differences on six items: the albino group claimed to have significantly more physical problems (in particular headaches, sweating palms, blinking and general 'troubles') than the control group; and significantly more of the control group expressed shame concerning their appearance, and a general unwillingness to speak to strangers.

(5) According to the assessments made by the two clinical psychologists of data collected from the 'Whys' appended to various adjustment items, the albinos were found to be significantly better adjusted than the controls. The albino females again showed significantly higher scores, indicating better adjustment than the controls; there was no significant difference between the males in the two groups.

7.5.2 Section III on Attitudes and Problems

The results may be summarized as follows:

(1) The attitudes, expressed by the subjects, towards albinos were generally positive and there was no significant difference between the overall scores of the albinos and controls. The control males however were significantly less positive in their attitudes than the albino males were.

(2) The mean scores of the two groups on most attitude items showed no significant difference. Both groups showed positive attitudes towards marriage and towards close contact, such as in sitting, working or eating together, or in being friends with albinos.

(3) Two items showed significant differences between the groups. The albinos claimed to have greater difficulty in obtaining employment, and the controls claimed that there is uncertainty at the end of the life of the albino, that they do not die naturally, but either disappear or wander away.

(4) The main problems of the albino, according to the subjects, appeared to be of a physical nature, in particular concerning his skin and eyes. There was much ignorance, many misconceptions, and misunderstandings, surrounding the etiology and inheritance of albinism.

(5) There was limited contact with social worker by the two groups, but the social worker was seen as counsellor, provider of material assistance and 'helper'. A need for her services as provider of material assistance was indicated by the control group. The albino group expressed the expectation that help for them would be an outcome of the study.

(6) The purpose of the interview was, generally, correctly assessed and according to the interviewer the majority of the interviews proceeded smoothly.

7.5.3 Discussion of the Results with Reference to the Aims of the Present Study

The results, as outlined above, with reference to the aims[10] of the present study were as follows:

(1) The first aim was to study the comparative level of adjustment of young albinos, specifically in the spheres of interpersonal relations, emotional life and physical well-being. The results pertaining to this aim showed that the albinos and the normally pigmented controls showed a similar level of adjustment. There was a tendency for the albino females to show a better level of adjustment in comparison with the controls than the albino males. The data also showed that the albinos had significantly more problems of a physical nature than the controls, these problems

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10. See page 4 of the present study.

were on the whole related to their condition. The spheres of interpersonal relations and emotional well-being appeared from the results to have an extensive overlap, the albino appeared to function as well as the controls in these areas and two items showed results that suggested that the albinos might have a better self-concept than the controls.

(2) The second aim was to compare the attitudes of a normally pigmented control group and an albino group with regard to albinos. The results of the data collected showed that the attitudes of the control group were generally positive and very similar to those of the albino group. The attitudes of the control males were, however, significantly less positive than those of the albino males; there was no significant difference between the females in the two groups. The problem that became most apparent from the results pertaining to this aim was the attitude towards death. Significantly more of the control subjects claimed that they believed that mystery surrounds the death of albinos.

The results again showed that the main problems of the albino were physical and associated with the condition of albinism and that there was ignorance with regard to the etiology and inheritance of albinism on the part of both albino and control group.

(3) The third aim was to make suggestions for a social work service relating to albinos. Further data were collected to make these suggestions more relevant and the results indicated that the albino and control group had had limited contact with social workers, nevertheless they thought that social workers could help with their problems. The role of the social worker was seen to involve both counselling and environmental managing. The albinos expressed the expectation that improved services for them would be an outcome of the present study. Further discussion of this aim will be an integral part of the following Chapter.

7.6 Conclusion

These results are based on the personal reports of the individual subjects and on their conceptions of their adjustment, problems and attitudes. From this point of view the results should be treated with caution, since there has been no external observer

to arbitrate on the validity of the subjects' statements. This is, however, the material with which the social worker must work. The way in which a person states his own problem provides the starting point for all social work treatment. For this reason the comparisons and results as reported above, although based on self-report and to some extent impressionistic will, nevertheless, give valuable information on the nature of some of the features of adjustment and some of the problems encountered by albino youth in Soweto. The data collected will also be of value in making the required social work response relevant to expressed needs.

CHAPTER 8

CASE PRESENTATION

8.1 Introduction

Despite the many advantages and contributions of survey research,

> 'one basic shortcoming is that the individual is often lost ... The individual becomes a part of N, the total sample population, and in this process the ego, by which is meant the dynamic self, the individual in his social situation, disappears'.
>
> (Kent and Barg, 1969, p. 227)

For this reason it was considered important to reintroduce the individual as a whole person into the present study at this point.

Bennet (1976, p. 623) has emphasized that

> 'the whole is not only more complicated than the sum of its parts, it is also quite different. The whole - that is, the whole person - is unpredictable, illogical, emotional, and a great deal more important than the separate pieces'.

Similarly Hofmeyer and Meiring (1976) have outlined the value of a holistic approach in therapy. They state that people must be treated as 'people, not cases', and that when patients tend to take up permanent residence in hospital wards it is often because the physician has not put this principle into practice.

Conclusions, discussions, and planning concerning people, cannot be based on statistics alone. Statistics tend to be abstract and theoretical, and concrete examples are required to illustrate the reality of the whole psychosocial person. It is important, as Keefe (1976, p. 11) states, for the social worker to understand the gestalt of the client's social role, feeling state, identity behaviours, and cognitive processes. Case material is then frequently used to illuminate rather than to prove the theoretical positions advanced (Wright, 1960).

Because of the psychologist's and the social worker's basic interest in the individual and his adjustment, it was considered particularly relevant and important that the significance of the individual should be made apparent in this study. The professional worker who is concerned with the adjustment of the individual, and with his quality of life, wants to know how to become effective in therapeutic ways in assisting people to find satisfying levels of adjustment. Always fundamental in the obtaining of this knowledge is the collection of case histories which are analysed and, either with or without substantiation by other data, used for deducing principles of more effective therapy. Such reports are needed in this context, as they were required by Balint (1957) in his study of the doctor-patient relationship, to demonstrate aspects of professional thought and practice that might be in need of revision or enlightenment. Balint suggested that he would therefore base his 'deductions on concrete clinical observations of individual patients' (Balint, 1957, p. 5), and he proceeded to illustrate his remarks throughout the text with extensive case material.

The aim of the present study is to view the adjustment or maladjustment of the albino as comprehensively as possible. After studying the results of the statistical analysis of the information gained from the schedules the writer found that they did not give a sufficiently global view of the albino as a whole person. Further data were required in order to make some assessment as to the reliability of the study, to gain more information on some individual subjects and to clarify some specific needs of the albino to which the social worker should respond. It was therefore planned that the case histories of two subjects should be studied in detail.

It is of course possible that this method of treating the material available might have been preferable and that the intensive study of the case histories of all of the thirty-five albinos, who represent the subjects here, might have yielded more interesting, reliable and informative data. The writer, however, believes that both of these methods, i.e. the statistical analysis and the case study, have their merits and can be used to complement each other, producing new insights as well as useful information.

8.2 The Purpose of Studying Case Histories

The purpose of studying cases in detail in the present context was to produce more useful data that would illustrate the living situations in which the problems under discussion had occurred.

The aim of conducting an intensive study was threefold:

(1) To obtain further information to supplement the results of the statistical analysis of the responses to the schedule;

(2) to study subjects who reflected the antitheses of the study, i.e. one of whom showed good adjustment, according to his schedule score, and the other of whom showed poor adjustment and a low schedule score, to compare these two for differences and to show whether, in fact, their case histories could confirm their status according to their schedule results;

(3) to show where and how social work or other professional intervention was needed.

8.3 Method and Procedure of Selection of Subjects for Intensive Study

In order to obtain information relating to each of the aims as outlined above two albino subjects were selected for intensive study. The method used was to take the top ten scorers and the lowest ten scorers in the albino group and select the subject for whom the most information was available. The selected two subjects were well-known

to the writer, who had visited them at their homes in Soweto at least three times. Both subjects had also been interviewed twice by the writer at her office. In addition they had siblings affected with albinism and the writer had held discussions with these siblings, as well as with other members of the families. With the information obtained from these sources, together with the data collected during the present study, it was easier to obtain a global view of these two subjects than many of the other subjects in the albino group.

The procedure was to outline the family background and history of each subject, to discuss his responses to the schedule in detail and then to draw conclusions with reference to the aims as set out above. The subjects were then compared and further data obtained to support these conclusions.

8.4 The High Scoring Subject

This subject is a nineteen year old male who will be known here as Thabo[1] (see Fig. 8). He scored 55 points (the maximum being 60 and the mean for the albino group being 44.06) on the adjustment scale in the schedule, and throughout the schedule reponded in a well-adjusted manner to items concerning his social and emotional well-being. His only problems were his physical problems, which one might expect, and which in this case were closely related to his albinism. It appeared that he had succeeded in containing these specific physical problems to the area where they belonged and had not allowed them to invade or to encroach upon his well-being in the other areas of his life.

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1. The name Thabo is used here as *a nom de plume* to preserve confidentiality.



Fig. 8. High-scoring albino subject, Thabo.

8.4.1 Family Background of the Subject

Thabo's family originated from Thaba'Nchu and are members of the Barolong tribe of the Southern Sotho peoples. Thabo lives in one of the suburbs of Soweto (see Fig. 9) where there are houses of all types and where lower, middle and upper classes live side by side. Thabo's own family may be classified as upper middle class. His grandfather built up his own small grocery business and ran the shop which was sited next door to his house. He had sufficient income to build additions on to the basic square four-roomed Soweto house, and added such amenities as a pitched tiled roof, a verandah, an extra bed-room, inside bath-room and a garage. Thabo has always considered this house his home, and some of his siblings, particularly his albino sister, often live at this house. The grandfather and grandmother however have since died and Thabo's parents have moved to Bloemfontein where they have set up their own business. From hearsay they appear to be quite prosperous and pay occasional visits to Soweto and

Johannesburg. The Soweto shop is now run by one of the grandfather's daughters (a paternal aunt of Thabo), whose husband has left her with a young family to support. Thabo regularly helps in the shop during his school holidays. The family income is undisclosed but is sufficient to afford the family some luxuries and to allow them to run a motor car.



Fig. 9. Thabo outside his family home in Soweto (with thanks to Thabo, who provided this photograph).

Some details from the family pedigree are shown in Fig. 10. The information indicated on the pedigree was obtained from Thabo (III.3), his albino sister (III.2) and his paternal aunt (II.1), and has not been verified from any other source. Only the side of the family on which there was a history of albinism has been included.

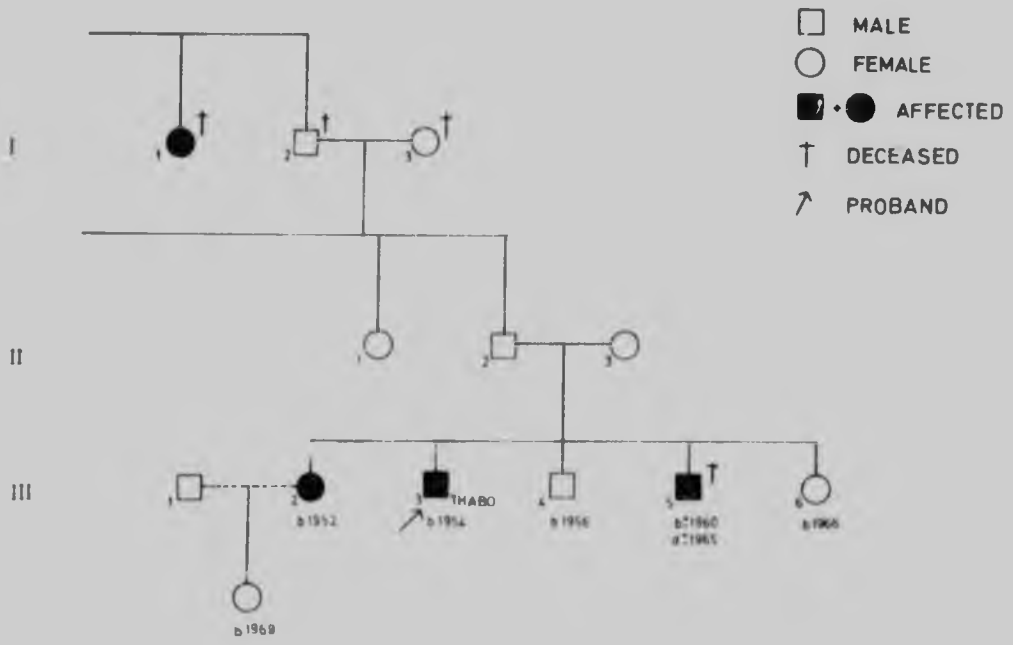


Fig. 10. Pedigree of family of albino subject, Thabo.

According to Thabo there was a paternal great aunt who was also affected with albinism and this family history may be partly responsible for the fact that the paternal grandfather so readily took in and cared for his albino grandchildren. The knowledge of the disorder in the family may also account for the ready acceptance of the albino children and the fact that no measure of rejection appears to have occurred. It is evident from the history that Thabo's parents were from the same Basotho tribe; they did not however show consanguinity, but both carried the gene for albinism. They then had a 25 per cent risk that every child they produced would have a double dose of the gene for albinism and would therefore manifest the condition. They were unlucky that this happened three times among their five offspring, but this is not unknown, and the writer is aware of several other families in Soweto where there are three

affected children. Thabo's sister has a lower educational level than he does, she has an illegitimate child and is not yet married, although she is now twenty-two years of age These circumstances are commonly found among the other albino females known to the writer.

8.4.2 Thabo's Response to the Schedule

At the time Thabo was interviewed for this study he was on holiday and was about to return to Bloemfontein where he was at boarding school. He was to start his final school year and write his matriculation examination at the end of that year (1975).

Thabo stated that he was eight years old when he entered school and had not repeated any years of schooling. He planned to apply for University entrance, once he had matriculated, with the intention of studying for the Bachelor of Science degree in Pharmacy. He claimed that he was a member of the Nederduits Gereformeerde Kerk and enjoyed church-going. He listed his other interests as reading, listening to the radio, music, playing tennis and watching soccer.

In response to the items on the second section of the schedule Thabo gave a very positive and seemingly realistic, though sometimes contradictory, picture of himself. He claimed that he was quite satisfied with what he did every day, and did not often day-dream nor have any unusual habits. He was happy most of the time, especially when he was at school, at home he was 'usually disillusioned and lost his temper quickly'. Nevertheless he did not often feel like running away from home, was quite happy with his family and had a feeling of belonging He also felt he had a happier home life than many other people. He made plenty of friends, found it easy to speak in a group of people and did not think that

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others treated him unfairly. Thabo claimed to get on well with people, and added that he did not often get angry and did not blame others for his troubles. He usually spoke to strangers on the bus or train. He thought that he often became anxious, but he related this anxiety to examination time and to situations when he was 'expecting something to be done to him'.

Physical problems related to his condition did bother Thabo, although he denied having sweating palms, or blinking frequently. He claimed that he did not miss much school because of physical problems, but found 'headaches coupled with sore eyes' to be his biggest problem. He had frequent headaches and explained these usually as a result of his eye weakness, for example, he added that when he was 'reading hard his eyesight became strained' and a headache often followed. Thabo did not express any feelings of shame regarding his physical appearance and did not feel that other people were always looking at him.

More information was available from Thabo's responses to the items in Section III. He considered the main problems of albinos to be eyesight, pimples on the skin and cracked lips. He did not however think that albinos should be restricted to certain types of employment and stated 'I realize they can do all kinds of jobs' and should have no difficulty in obtaining work. He was quite happy to work with, sit with, eat with and make friends with other albinos, and did not think their skin problems affected him in any way. He indicated that he had accepted that albinos die at the end of their lives like other people[2].

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2. Although in the course of further discussions with Thabo, after the interviewing for the present study was concluded, he stated that he had been very worried as a younger child by the myth that albinos did not die, and he had wondered what he was supposed to do, however as he grew older he accepted that the myths were nonsense and that he would die like any other person.

Thabo claimed that marriage between normally pigmented persons and albinos or between albinos is possible 'if they love each other'. He had however not yet arrived at the stage of attempting to find a marriage partner and no information was available on his dating habits. It would be interesting to follow-up Thabo during the next ten years, to observe his behaviour in this connection and to research these problems more thoroughly.

In response to the item concerning the causes of albinism Thabo said 'from my study of genetics I have come to understand genetic failure in parents'. When asked about the colour of the children of albinos he said 'it all depends on the genetic make-up'. He did not add, however, that the majority of such children will be normally pigmented, which might indicate that he had limited understanding and that further explanation and genetic counselling is required here.

Thabo commented further, that 'I suggest albinos try to get themselves well-educated, so as to be socially acceptable and also be able to get good jobs, well-paid, etc.'. He seemed to be purposefully applying this principle in his own life. On a follow-up visit to Thabo's home this year (1976), the writer discovered that he had failed some subjects in his matriculation examination. His determination to achieve, however, had not been dampened, and he was working in his grandfather's shop and studying by correspondence, so that he could rewrite examinations in the required subjects at the end of the current year, and gain a university entrance qualification.

Finally Thabo commented on social workers, stating that they could be of help by obtaining a bursary for him, or perhaps a better job. He had not come into contact with or been assisted by social

workers previously. He assessed the purpose of the interview quite accurately saying 'you want to understand me as an individual, and my related problems, and maybe come up with a solution to some of my problems'. The interview was held at Thabo's home and the interviewer added that the 'respondent is very intelligent, answered questions with great insight. The interview setting was very good and relaxed'.

8.4.3 Conclusion

It appears then that, according to Thabo's response to the schedule and to the writer's impressions after interviewing him and studying his case history, he is a fairly well adjusted person. He seems to meet the requirements of English and English's (1970) definition of adjustment[3], to show a reasonably harmonious relation to the environment, to be able to obtain satisfaction for most of his needs and to meet fairly well the physical and social demands put upon him, as far as could be ascertained from the data available. Nevertheless he indicated a need for assistance regarding his specific physical problems and a need for genetic counselling to improve his understanding of his condition.

He seemed to have achieved a fair amount. Simply reaching the stage of writing his final school examinations, without repeating a year, is an achievement in a society where the majority drop out of school long before they reach this stage. In pursuing his goals and in coping with failures and problems, as well as in his relationships with others, and his acceptance of his albinism,

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3. See page 13 of the present study.

he appeared to show a good adjustment to reality. This case study gives further data to substantiate his schedule score, which indicated that he was relatively well adjusted, and appears to confirm his status as determined by the statistical analysis, and the clinical psychologists' assessment.

8.5 The Low Scoring Subject

The selected subject in the low scoring group was also male, aged nineteen years at the time of the interview, and will be known as Doda[4] (see Fig. 11). His score on the adjustment section of the schedule was 34 points (where the maximum was 60 and the mean for the albino group was 44.06 points). He appeared to be poorly



Fig. 11. Albino subject, Doda (right), and his identical twin brother.

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4. The name Doda, is used as a *nom de plume* for this subject to maintain confidentiality.

adjusted according to his responses to the schedule, was said to be 'lazy' by his school teachers, and at the time of interviewing (early in 1975) was a Drop-out, neither attending school nor employed, but biding his time by roaming the streets in the company of other unoccupied youths.

8.5.1 Family Background of the Subject

Doda's family are from the Moshoeshoe tribe of the Basutho people and they still have strong ties with their rural home in Lesotho. The family have recently been rehoused in a newly built suburb of Soweto, having lived for many years in a derelict, and recently demolished, slum area. Their new house is the basic four-roomed Soweto house and the area is still underdeveloped, with few gardens or trees and a bleak outlook over the open veld. The houses are all identical, pale grey in colour and zinc roofed. They face onto untarred roads which are rutted and eroded in the rainy season.

Doda lives with his father and a married sister. His mother and grandmother (see Fig. 12) share their time between the homes in Lesotho and Soweto. There are also at times other female members of the extended family living in the house. Doda's father is employed as a labourer at an engineering works, and his mother is unemployed. The family income is sufficient only to supply the basic necessities and they survive with the minimum of furniture, clothing and food.

The family pedigree is shown in Fig. 13, and is based on information (which has not been verified) obtained from Doda, his mother and grandmother. The pedigree indicates only some details of three generations on the side of the family on which there was a history of albinism



Fig. 12. Doda and some of his family (clockwise, from top left) his twin brother, Doda, his mother and his grandmother.

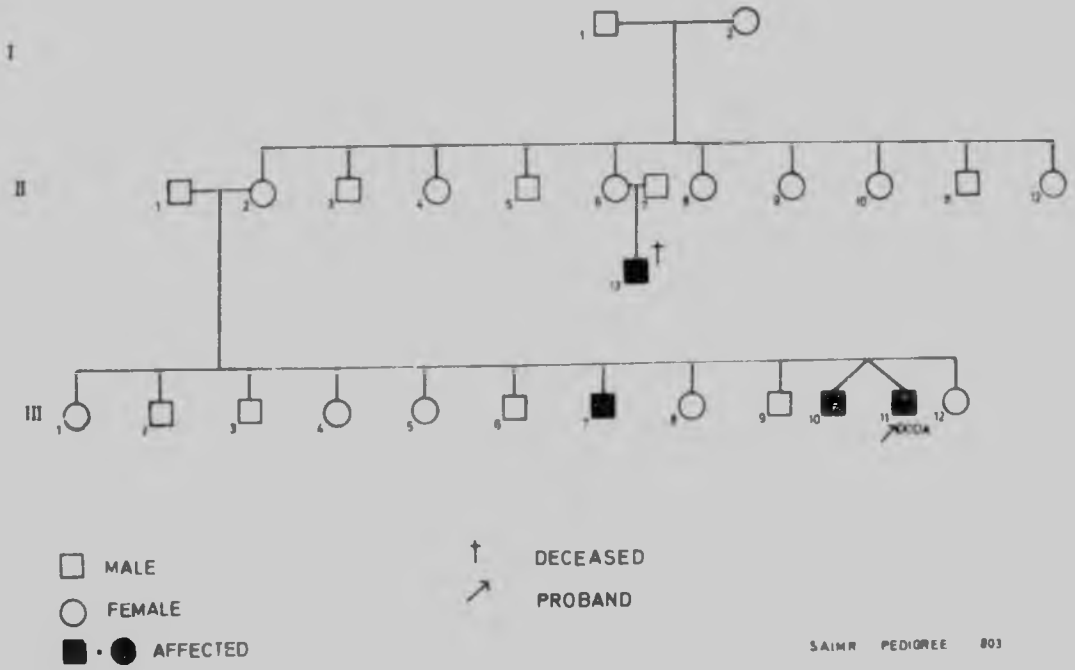


Fig. 13. Pedigree of family of albino subject Doda.

Again there was a family history of albinism, the older albino brother (III.7 on the pedigree) however, had left the family circle and lived and worked in Natal. The majority of the other children lived in Lesotho and visited Soweto occasionally. Two of the twelve children died in infancy, as did the male affected child of Doda's maternal aunt. The fact that Doda's albino twin was present and lived in the home did not seem to have helped with Doda's adjustment problems. The twin himself had only achieved slightly more than Doda and scored slightly higher on the schedule.

8.5.2 Doda's Response to the Schedule

Doda was interviewed in the kitchen where most of the family activity and conversation took place, and where a chair was available for the interviewer. The twin brother and other members of the family wandered in and out at will.

Doda started school at the age of eight years and repeated his second year. He continued to his eighth year at school (Std. VI) and then failed again and was asked to leave. The school he attended was run by the Roman Catholic Church; Doda joined the church, and he and his twin brother have been assisted by church workers for many years. Since leaving school Doda has had one job in a factory, however he was dissatisfied there and left after one week. He has been arrested once for a minor offence in connection with the reference book he is required to carry. His hobbies included reading, listening to the radio, gardening, attending films with friends, and playing cricket occasionally.

In response to Section II of the schedule, on adjustment items, Doda claimed that he was not very happy. He said he had 'no money to go where he wished to, had not enough clothing,

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In response to Section II of the schedule, on adjustment items, Doda claimed that he was not very happy. He said he had 'no money to go where he wished to, had not enough clothing,

and was unable to find employment'. Interestingly however he stated that he was satisfied with what he did during the day (which appeared to be nothing), but that 'like any other person there's a day on which you feel sad and disgruntled'. He added that he often had day-dreams and had the habit of 'brushing my head when talking to people I am not used to'. He claimed that he had plenty of friends and that he was quite at ease when speaking in a group of people.

He had ambivalent feelings concerning his family, he said that he usually felt wanted by his family, but often felt like running away, because 'I don't get what I want'. He cried often, especially when he lost his temper, particularly with his younger sister, who 'won't listen'.

Concerning other people Doda thought they treated him unfairly. He stated 'some people have a lot to say about us in trains, etc. They start a topic and talk about us'. He added however that he did not blame other people for his problems, but rather blamed his parents, for 'they do not take care of our needs'. He commented that other people are always looking at him, 'that things happen everyday, everywhere - I don't know why'. It seemed from this response that Doda showed a lack of acceptance of himself as an albino and a lack of insight into the difference between himself and others. From a study of the other albinos' responses however it appeared that the majority denied that people looked at them and thus they might be evading reality whereas Doda in this case was admitting it, although only partially, since he added, 'I don't know why'. It might be that he is using his energies to reject his condition, where through counselling leading to an acceptance of it, these energies could be released to cope with other areas of his life. He seems also to be caught in the circle of helpless-

ness described by Seligman (1972), in which his life does not bring any rewards, so that he does not try new activities and therefore again does not get any rewards. Counselling in this case might be aimed at breaking such a circle, if it was shown by more extensive investigation, to exist.

Physically Doda had many problems too, he said he became sick frequently and had missed a fair amount of schooling for this reason. He claimed to have pains (which might possibly be psychosomatic) in the body and in the knees, so that 'I can hardly sit flat on the ground'. He often had headaches, especially when the sun was hot. He had undergone eye treatment at the local eye hospital. He had also had a head injury as the result of an assault. He claimed not to be ashamed of his physical appearance although he stated 'that some time back I used to be ashamed, because I did not realize that there were other people like myself. Today there are others who even drive cars. That makes me most happy'.

The items in Section III on attitudes elicited many interesting comments from Doda. He said the main problems of albinos are 'brown spots on the skin, weak eyesight, (better at night), can't stand the heat'. He maintained that certain types of employment are required by albinos, since they could not stand the sun and needed shade, and that it was difficult for the albino to get work. He said that albinos had average intelligence but could not live like everyone else, because of all their problems. They also had specific characteristics, according to Doda, such as being cheeky and losing their tempers.

Regarding marriage Doda thought that albinos might marry either normally pigmented or albino partners, but he added 'I don't prefer to marry'. This comment was not probed in the interview and this

attitude toward marriage should be explored further with this subject. There is also no further information available on his experiences, or lack of them, with the opposite sex, and the reasons for his statement here are unknown. He did, however, claim to have albino friends and stated that their skin problems did not affect him in any way.

To the item concerning the causes of albinism Doda responded that 'God meant people to have them'. He added however that 'albinos never have albino children, they always have black children'. On the subject of death he responded aggressively, stating 'I know why you ask this question. People say we are disappearing. This is nonsense. We die of course'. Nevertheless his aggression might have indicated that the myths surrounding the death of albinos presented a problem that bothered Doda and his reaction might show a need for further discussion of this topic with him. When asked about social workers and how they could help he said 'they could not help, because at this moment I've never received help from any of them'. Finally he responded to the item regarding reasons for the questions with 'you want to know about our lives'.

After the interview using the schedule for the present study Doda together with his twin brother approached the writer and the interviewer aggressively, stating that they needed financial assistance, and demanding to know what was going to be done with the information collected, was it going to be used at the University 'to make others laugh at us?' After a discussion which involved a release of their feelings and which concerned further information regarding the research project and its aims they withdrew, reassured. It became even more apparent to the writer, however, that these subjects would benefit from the assistance and coun-

selling which could be offered by a social worker.

8.5.3 Conclusion

It appears from the information obtained from his schedule, from the writer's knowledge of this family, and from the data obtained from the case study, that Doda needs assistance both practically, by referral for suitable employment, and through the counselling offered by both social worker and geneticist. Genetic counselling, in its broadest definition, which includes enabling the client to accept his condition, understand its symptoms and prognosis, and make a realistic adjustment to it, would be beneficial to Doda. Similarly case-work, which would enable him to make more satisfying adjustments to his problems and to develop more adequate coping mechanisms, would benefit him. The provision of facilities for such counselling will be discussed in the following chapter.

The additional data from this case history, in particular Doda's negative attitudes towards his family, to employment, to marriage, to 'others', as well as his problems concerning possible psychosomatic pains, and his anxiety over death, seem to indicate that he is not adjusting adequately to his life situation. This evidence confirms the results of the statistical analysis of the schedule which scored Doda among the poorly adjusted subjects.

8.6 Comparison of the two Subjects

It appears that the relatively good adjustment of Thabo may be attributed to several factors which are absent in the case of Doda and contribute to his poor adjustment. The most important of these factors appears to be the basic acceptance of being an albino. Thabo appears to have achieved this self acceptance where Doda

does not appear to have done so. There are of course many factors operating in the two cases which contribute to the acceptance or rejection of oneself as one is. Thabo views his family as strongly supportive, whereas Doda sees his family as non-supportive. This support presumably enables Thabo to appear more stable and to cope with his condition whereas Doda, who is denied this support, appears to be incapable of coping with life's demands. This family stability and self acceptance contributes to help Thabo cope with failures and progress towards achievement; Doda however is unable to progress, but continues bound by a circle of failure. From this point of view the two look as different as their schedule scores may suggest, and appropriate social work or psychologist intervention in the case of Doda may take the form initially of family therapy.

The two subjects however have in common a lack of total understanding of their condition and they could both benefit from genetic counselling. Possibly Thabo would require just one session, whereas Doda could benefit not only from several sessions of genetic counselling, but also from the counselling offered by a social caseworker or a clinical psychologist. Both albinos have physical problems, the treatment of which might be partially undertaken by a medical specialist at a nearby accessible clinic specifically set up for dealing with genetic disorders. They would both benefit too from referral to, and treatment by, dermatologists and opthalmologists in order to reduce their medical problems to the minimum.

8.7 Discussion and Conclusion

If there is to be intervention initiated by a social worker or a clinical psychologist then it must be relevant to the expressed

needs. Several needs have become evident through the study of these two case histories. Firstly, although one subject was relatively well adjusted and the other relatively poorly adjusted, they both showed a need for fuller understanding of their condition, of its genetics, physical side-effects, and the possible psychological and social side-effects. Secondly, the poorly adjusted subject showed a need for both individual counselling to deal with maladjustment problems, negative attitudes and anxieties, as well as family therapy to involve his seemingly non-supportive family in his rehabilitation. Thirdly, the poorly adjusted subject showed a need to be accepted by the community and intervention in this regard would have to be on the community level.

In assessing the value of the case history the writer believes that many of the problems portrayed in these two accounts are common to other subjects in the same situations. It is also evident that the case history gives useful additional information and particularly insight into the needs of the subjects as individuals and as albinos. Answers to problems are frequently sought through knowing the individual and focusing on more than his handicap (Towle, 1965). It is possible that further additional data would have been obtained if these case histories had been submitted to or discussed in consultation with a clinical psychologist. A fuller analysis might have been possible with help from this source.

It must be accepted however that many topics of importance to the problem of adjustment to disability (in this case albinism) do not appear in these pages. Reasons for exclusion are various and, as Wright (1960, p. xviii) states, the writer's 'theoretical background and range of experience and competency naturally tend to prescribe certain questions and exclude others'. The scope

of any study must perforce be limited and the writer believes that the statistical analysis of the schedule responses, and the clinical psychologists' assessments of the same responses, together with the assessment (admittedly somewhat subjective) by the writer of two case histories would give sufficient information to define some needs, propose some action, draw some conclusions, as well as make some suggestions for future research.

In conclusion then the case history approach to the study of the individual is seen to be a necessity for the provision of data which are complementary to the material obtained from the statistical analysis approach. The case history approach should not be considered superior, there is much to be gained from studies of groups of affected individuals, especially when compared with matched groups of normal individuals. It was the background knowledge of the information gained in this way that enabled the writer to study the case histories of the individual subjects and to ascertain common needs and possible methods of meeting these needs. The conclusions of the present study and recommendations for action then are based on the results of the statistical analysis together with the case studies as presented here.

Discussions on the genetic counselling services, at present available as well as on the expansion of these services to meet the needs as exposed in this Chapter will be covered in the following Chapter.

CHAPTER 9

A SOCIAL WORK SERVICE FOR THE ALBINO

9.1 Introduction

In order to provide information regarding the third aim[1] of the present study, which was concerned with a relevant response from the social worker to the problems uncovered in the course of the study it is necessary to outline the context in which a service for the albino could be established. Albinism is a genetic disorder and since the major problems of the albinos appear to be related to his disorder and to his need for genetic counselling the social work service discussed here is set in the department of Human Genetics. There are obviously other social work services from which the albino could benefit but they are not the concern of the present study.

The present Chapter then will cover a brief outline of the historical background of genetics clinics, and specifically the development, structure and function of the Department of Human Genetics in Johannesburg; a discussion of the development of the social worker's role within this department and a delineation and explanation of her service, teaching and research duties, with particular emphasis on their relevance to the albino and including recommendations for expansion to incorporate the suggestions from the findings of the present study; and a discussion on the content of courses in genetics for social workers to enable them to cope more effectively with individual and family situations involving genetic disorders, such as albinism

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1. See page 4 of the present study.

9.2 Historical Background

'The first hereditary clinics were established in 1940 at the University of Michigan and in 1941 at the University of Minnesota' (Schild, 1971, p. 471). Since then genetic centres have sprung up all over the world. In 1969 there were 196 genetic units in the U.S.A., 138 of which offered genetic counselling services. That same year the International Directory of Genetic Services listed 566 genetic units, of which 381 indicated that they provided such services.

The motivation for employing social workers in these genetics units originated from the

> 'observation that the social and psychological problems engendered by the genetic advice and information are potentially threatening to the stability and integrity of individual and family functioning'.
>
> (Schild, 1971, p. 474)

Hollis (1964, p. 173) too recognized that physical conditions have characteristic effects on personality functioning and that they are likely to play a significant part in interpersonal difficulties, they also 'can change the self-image and distort relationship between husband and wife and between siblings'. How much more so, then, could long-lasting genetic disorders disrupt the family. Social workers were gradually introduced into genetic clinics to deal with the problems produced by the presence of these disorders in families.

Neser and Sudderth (1965) were amongst the first to emphasize the importance of introducing courses on genetics into the social worker's curriculum. Schild (1966) then wrote about the 'Challenging Opportunity for Social Workers in Genetics', and was followed by Schultz (1966) who was concerned with 'The Impact of Genetic Disorders'. In 1966 Evans and Krush, who were social workers in

geneticɛ units in London and Omaha respectively, met in London to discuss the scope of their roles. They outlined the following components of the social worker's role (Evans and Krush, 1967):

(1) She enlists the co-operation of family members in medical genetics studies.

(2) She evaluates attitudes and feelings of individuals toward the disease which is present in the family.

(3) She maintains an empathetic attitude and feeling of warmth towards the individuals in the study, and may be required to interpret the interests of the research team and the nature of the study to family members to ensure their continued co-operation.

(4) She is knowledgeable concerning available community health and welfare resources to which family members may be referred if problems develop or are present.

(5) She conducts research on psychosocial implications of hereditary disorders.

Subsequently in 1969 Schild carried out a survey, in the United States, of eighty-six genetics units providing genetic counsell.g and found that 50 per cent employed social workers in staff positions, and 90 per cent used social workers in the provision of services to their clients (Schild, 1971, p. 472). As a result of her research Schild also outlined a more extensive role for the social worker[2]. In 1972 six social workers from various countries met in Montreal for discussion on the role of the social worker in genetics. The conclusions of the meeting were not published, however Krush, (1974, personal communication) stated that the great diversity of activities performed by each social worker became apparent and this diversity was often dependent upon the attitude of the geneticist in charge, and the extent of the functions of the particular department of genetics.

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2. See page 154 of the present study.

9.3 The Background of the Department of Human Genetics, Johannesburg

The present Department of Human Genetics, of the School of Pathology of the University of the Witwatersrand and The South African Institute for Medical Research, is a very new department. It grew out of two units, namely the Cytogenetics Unit which was formed in 1961 for the purpose of studying human chromosomes, and the Sero-Genetics Unit which was formed in 1968, to study the genetic markers in the blood. In June 1975 a Chair of Human Genetics was established and the new department was constituted. The first incumbent of the chair was Professor Trefor Jenkins who had previously been the head of the Sero-Genetics Unit. The only other Department of Human Genetics in South Africa is attached to the University of Cape Town Medical School and was established in 1973.

In 1971 the writer joined the staff of the Sero-Genetics Unit and this marked the first appointment of a social worker to a post in genetics in South Africa. At that time the staff consisted of a doctor, three technicians and one assistant. The staff establishment of the present Department is three medical doctors, who function as geneticists, one social worker, a biochemist, nine technologists, two secretaries, a nursing sister, two assistants and occasional students with *ad hoc* appointments.

9.4 Functions of the Department of Human Genetics

The main function of the department, at the time the writer was appointed in 1971, was research, with only a minimum of time being spent on teaching and service. However the functions have expanded rapidly over the past five years to encompass the wide range of activities carried out by similar departments of human genetics elsewhere in the world. These are as follows:

(1) Service: which includes the provision of

(i) Counselling services: four genetic counselling clinics have been set up in the last four years. The first was initiated at The South African Institute for Medical Research (S.A.I.M.R.) and was held initially once a week. It has now had to expand to a twice weekly service to cope with the demand (approximately eight new families per week). The second was a weekly clinic organized at the Transvaal Memorial Hospital for Children. The third was established at Boksburg-Benoni Hospital and is held monthly. The fourth and most recent is the clinic (set up in March 1976) at Baragwanath Hospital, which is also held once a month until the demand increases. Where the clinics are based at hospitals, regular hospital fees are paid, otherwise there is no charge for the counselling service. Black patients may attend the S.A.I.M.R., Boksburg-Benoni and Baragwanath clinics. Albinos have been interviewed at all three clinics; the majority in the past, however, attended the S.A.I.M.R. clinic. With the new and more convenient clinic now available at Baragwanath this pattern will probably alter. Approximately fifty new patients are seen monthly at these clinics.

(ii) Diagnostic Services: particularly relating to chromosomal and biochemical studies. These services also include pre-natal diagnostics and provision of facilities for the testing of the foetus *in utero*, through the amniocentesis[3] clinic, which is co-ordinated by the Department and held once a week.

(2) Teaching: which involves the teaching of human genetics to:

(i) Medical students: at the undergraduate and post-graduate levels.

(ii) Science and genetics students.

(iii) Paramedical professions, such as physiotherapists, speech therapists, occupational and remedial therapists and nurses.

(iv) Social workers: in training and in practice.

(v) The public: interested groups, such as adult education, women's groups, welfare and religious organizations.

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3. Amniocentesis is the word used for the procedure whereby amniotic fluid is withdrawn from the uterus. In the present context the procedure is carried out for the purpose of diagnosing a genetic disorder in the foetus and is usually performed between the sixteenth and the twenty-second week of pregnancy.

(3) Research: This is carried out in four major areas:

(i) Population genetics: this involves a study of the genes in populations.

(ii) Genetic linkage studies: which are concerned with the linking of disorders to genes.

(iii) Biochemical defects: defining of biochemical defects in certain inherited disorders and the application of such information to early detection and prevention of these disorders.

(iv) Genetic counselling: there is a constant need to evaluate genetic counselling. The accumulated experience of four years of this service, in which over 500 families have been interviewed, will be subjected to careful analysis: a project has been designed to undertake the evaluation of techniques and results of genetic counselling.

9.5 The Role of the Social Worker in the Department of Human Genetics, Johannesburg

The skills of the social worker can be used in the Department of Human Genetics at many levels and she plays an integral and dynamic part in carrying out the functions of the Department.

Schild conducted a study of social workers in genetics in the United States and obtained data from which she deduced that

> 'the social services furnished fell within the traditionally ascribed role in medical social work ... Interestingly many social workers took on a variety of functions in roles that could be categorized as social work "generalist"'.
>
> (Schild, 1971, p. 472)

The social services offered by the social workers studied are shown in Table 9.1, and in comparison the services of the writer, as social worker in genetics in Johannesburg, are shown in approximate order of priority on the same Table.

The services which are provided by the social workers in the U.S.A. are also provided in the Department of Human Genetics in Johannesburg, but with a slightly different emphasis on various

TABLE 9.1. COMPARISON OF SOCIAL SERVICES OFFERED BY SOCIAL WORKERS IN GENETICS IN VARIOUS CITIES IN U.S.A. AND IN JOHANNESBURG, R.S.A.

U.S.A. (from Schild's study)	JOHANNESBURG R.S.A. (from the experience of the writer)
1. Case work	1. Case work
2. Referrals	2. Interpretation and follow-up services
3. Social histories	3. Preparation of genetic pedigrees
4. Interpretation and follow-up services	4. Co-ordination of patient-clinic visits
5. Preparation of genetic pedigrees	5. Social histories
6. Co-ordination of patient-clinic visits	6. Research
7. Teaching	7. Referrals
8. Research	8. Teaching
9. Consultation	9. Consultation

services. In addition the social worker in Johannesburg is actively engaged in group-work with parents of patients suffering from inherited disorders, in a community organization project in the form of the newly organized Southern African Inherited Disorders Association, and in the co-ordination of the amniocentesis clinic for prenatal diagnosis.

It is not the purpose of this dissertation to discuss all the services of the social worker in genetics. However it is necessary to consider those aspects of her service which have bearing upon the findings of the present study, and have relevance to the provision of an improved service for albinos.

The role of the social worker will be considered in the three broad areas of the setting in which she works i.e. service, teaching

and research, with reference to the contributions in each area that can be made.

9.5.1 Service : Clinical Aspects

The major part of the service which the social worker in genetics has to offer to the albino and his family is in the field of genetic counselling. She also has additional counselling responsibilities and is expected to provide services of environmental management and referral.

9.5.1 1 Genetic Counselling

> 'The role of social work in genetic counselling can only be delineated in the context of what genetic counselling is and does, with knowledge of the features that characterize the method'.
>
> (Schild, 1971, p. 473)

Genetic counselling has been defined as 'a communication process which deals with the human problems associated with the occurrence of a genetic disorder in a family' (Fraser, 1974, p. 637). According to Fraser the process involves attempts by one or more trained persons to help the individual or family in five stages:

(1) The comprehension of medical facts, diagnosis, prognosis and management.

(2) The appreciation of the genetics of the disorder, and the risk of recurrence in relatives.

(3) The understanding of the options for dealing with the risk of recurrence.

(4) The choice of an appropriate course of action in view of the risks and family goals, and action in accordance with this decision.

(5) The making of the best possible adjustment to the disorder in an affected family.

The counselling carried out in the clinics in Johannesburg is based on these five stages, together with the knowledge that genetic disorders are often encompassed with strong, sometimes

repressed, emotions. In each interview the type of counselling is determined by the mode of inheritance of the particular disorder present in the family, by the emotional well-being of the family members, their educational background and ability to comprehend the information being given, and often by the severity of the disorder itself. The approach and philosophy of the geneticist will also influence the counselling service offered.

For the purposes of the present study discussion will concern only the counselling given with regard to recessive disorders, since this is the category into which albinism falls. Recessive disorders are perhaps one of the simplest types of all the genetic disorders to deal with in the counselling situation because of the clear-cut alternatives for the family. They may also however be one of the most depressing because of the high risk of recurrence[4] for parents who have had an affected child, or who both carry a gene for a recessive condition (the risk being one in four or 25 per cent of having an affected child).

The procedure in the Johannesburg clinics is usually for the social worker to conduct the initial interview, obtaining the particulars, and identifying details, and drawing up the pedigree of the family, investigating as much detail of relatives and as many generations as possible, and at the same time assessing the non-verbal cues of the family and their feelings concerning the problem. This information is then briefly communicated to the geneticist, who proceeds to interview the family, giving the genetic and medical information and answering any questions which

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4. Carter *et al.* (1971) categorise risks as high if they are between one in two and one in ten, and low if there is less than a one in 25 chance of having an affected child.

arise. The social worker participates in this interview, sometimes as a silent observer, and the family members may turn to her for interpretation, assurance, confirmation and acceptance during the course of the interview. It is necessary for the social worker to attend this interview, since she must have all the information available to enable her to carry out the interpretation and follow-up services which are required.

Five questions are generally discussed in this interview:

(1) Do I have the family disorder or will it develop in me in the future?

The response in the case of albinism is certainly in the negative, but further explanation is necessary regarding the fact that both parents carry a single gene for the condition, which does not show any obvious symptoms.

(2) Am I a carrier of the disorder?

The response is 'Yes', the gene for the disorder (albinism) is there and cannot be eradicated by any means at present available. Generally, so that the parents do not feel stigmatized, it is explained that every single person carries four or five genes for recessive disorders, but the gene pool is large and people seldom marry another person carrying the same 'bad' or deleterious gene.

(3) What is the risk to my children?

The risk is one in four or 25 per cent that a child, with the 'bad' gene from father and mother, will be an albino, because he has the double dose of the gene. Various aids may be used to explain this risk : diagrams may be drawn[5]; a pack of cards may be used where for example diamonds represent an affected child; a bag of marbles is used in some clinics, and for albinism the marbles could be selected, so that there is a ratio of three black marbles to every white one, to make the picture more realistic; another alternative is dice which are colour coded (Murray, 1975), three sides of each of two dice are coloured one way and three a different way (again black and white could be used in the case of albinism) to represent the normal and abnormal genes carried

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5. See page 11 of the present study.

by the parents. The dice are then thrown repeatedly to illustrate that the combination of two genes is a chance occurrence over which there is no control at present. The risk is there for every pregnancy and genes have no memory, so that the outcome of previous pregnancies make no difference to further pregnancies.

The risk to the grandchildren, or the children of the affected child, is frequently discussed at this point and again in the case of albinism, as with other recessive disorders, the risk is small. The probability of any black person in the population being a carrier is about one in 30, and it would require the marriage of the albino to a carrier of the gene for albinism to produce an albino child. The risk is 100 per cent only if the albino marries another albino with the same type of albinism.[6]

(4) Is prenatal diagnosis available?

No prenatal diagnosis is available yet for albinism, although research in diagnosing disorders in the foetus *in utero* is rapidly expanding and this service is available for some other serious recessive disorders. The problem to be discussed here, if the parents are enlightened, well educated and if they raise the question, is whether in the absence of prenatal diagnosis, they would elect to have a termination of pregnancy[7] on the basis of the 25 per cent recurrence risk. This would depend on how serious a condition they consider albinism to be and/or how severely their particular child is affected, as well as whether or not the family can cope with the problem.

(5) What is the prognosis?

With expert medical treatment, and if side-effects, such as skin cancer, and eye problems, can be controlled, prognosis for the albino child is reasonably good and he may lead a normal life. He probably has an almost normal life expectancy, although no data are available on this aspect for albinos living in Africa.

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6. See page 8 of the present study.

7. In terms of the Abortion and Sterilization Act, No. 2 of 1975, an abortion may be procured 'where there exists a serious risk that the child to be born will suffer from a physical or mental defect of such a nature that he will be irreparably seriously handicapped' (Government Gazette, 12 March 1975, p. 4). For further discussion on this subject see Jenkins and Kromberg (1976).

In order to make this type of genetic counselling entirely relevant to the albino in Johannesburg, and in order to incorporate the findings of the present study, it would be necessary to add certain other areas of discussion to the regular counselling session. Particularly important here is a discussion of death and the misconceptions that surround it, since this is a problem that worried many of the albinos in the present study. In this area, as in most other areas of counselling, it is very important that the counsellor has handled his own feelings on death and can cope with an open discussion on the subject. Depending on the concerns of the family, three other areas may need to be tackled in the interview: the concern about employment opportunities for the albino, the attitudes towards marriage of the albino, and the common misconception that albinism might be caused by divine intervention.

Genetic counselling then involves the presentation of genetic facts and 'high priority is given to counsellor neutrality and client self-determination' (Schild, 1971, p. 473). Advice as such is never offered by the geneticist nor by the social worker, but alternatives are discussed with the family and decisions are made by them[8]. The decision for the couple carrying the same recessive gene involves a choice between five alternatives (Kromberg, 1975):

(1) Another pregnancy (either with prenatal diagnosis if this is available, or without if the couple feel able to take the risk).

(2) Artificial insemination by donor (A.I.D.), using a carefully screened donor who does not carry the gene which has caused the disorder in the family (where detection of this gene is possible).

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8. It is the policy of the Department to interview both spouses together since the information given and the decisions to be made concern the whole family, and the staff believe that it is important that the husband as well as the wife, is involved in the decision-making process.

(3) Adoption, although this is not yet common practice among urban blacks, and there are very few black babies available for adoption.

(4) Foster care, although this may not be satisfactory since the natural parents may reclaim their child when their own circumstances change.

(5) Childlessness, which is a workable alternative where the mother has interests outside the home.

These alternatives are discussed in at least two interviews with the geneticist and social worker, and also in follow-up interviews with the social worker alone, so that there is a constructive resolution to the family problem, and coping strategies are developed.

> 'Follow-up has been found to be an absolute essential element in all programs dealing with health care .... not only because the initial counselling session may be highly emotionally charged, but also because counsellees may be unfamiliar with medical and genetic concepts, additional reinforcement of information transmitted as well as correction of misconceptions should be carried out during one or more subsequent counselling sessions'.
>
> (Murray, 1975, p. 119)

Patients are therefore seen at least twice by the genetic counselling team and frequently more often by the social worker alone.

Similarly team-work is a vital and integral part of the service offered. Teamwork here has the precise meaning that Bartlett (1961, p. 226) gives: it denotes

> 'one particular aspect of multi-discipline practice, namely the organized, continuous, and co-ordinated activity of a small group of individuals from two or more of the health professions, working together under the auspices of a single agency to further common objectives, such as patient care or programme development'.

The quality of the genetic counselling service provided is dependent on the successful co-ordination and integration of this type of teamwork.

Genetic counselling then is offered as a service to the albinos, by the geneticist and social worker in one or more interviews at the genetic counselling clinics in Johannesburg and at Baragwanath Hospital, near Soweto.

9.5.1.2 Additional Counselling Services

Social workers

> 'do not provide genetic counselling; they provide the services that assist affected individuals and their families with the dislocations and disturbances occurring as a result of the genetic diagnosis and information'.
>
> (Schild, 1971, p. 47

Several additional services are therefore offered by the social worker in the department of genetics. These services will be reported briefly here, with particular emphasis on responses they can offer to the needs of the albinos as determined by the findings of the present study. They will be considered as follows: crisis counselling, social group work, patient to patient counselling, family therapy and task-centred counselling.

(1) Crisis Counselling

The social worker in a human genetics unit must be prepared at all times to make herself available whenever the demand arises for crisis counselling.

> 'The birth of a congenitally defective infant transforms a joyously awaited experience into one of catastrophe and profound psychological threat: the apprehension of failure that is a normal part of the psychic anticipation of parenthood turns into reality - and the family finds itself in crisis'.
>
> (Goodman, 1964, p. 92)

The writer believes that social work intervention is urgently required and extremely valuable at this time. Simple channels of

communication must be set up so that families who have produced a defective infant and are in a crisis situation may have rapid access to social workers.

Olshansky (1962) has outlined dynamics that come into operation upon the birth of a defective child. He describes the 'chronic sorrow syndrome', particularly with reference to the mentally retarded child. The 'shattered self-adequacy syndrome' also occurs in many cases. The knowledge that one has a 'defective gene causes a momentous insult to the ego structure of the affected individual' (Schild, 1966, p. 26). Self esteem is especially vulnerable and expressions of inadequacy become manifest. The medical team dealing with this situation must be aware of these responses and be willing to acknowledge and handle them. The parents frequently feel intense shame, stigma and grief which runs a consistent course according to Engel (1961). He states that the initial phase is one of shock and disbelief followed by a developing awareness of loss, characterized by feelings of sadness, guilt and helplessness. The final stage is one of prolonged recovery during which the work of mourning is carried out and the trauma of the loss is overcome.

Rapoport (1970, p. 287) has determined the value of crisis intervention as follows: 'A little help, rationally directed and purposefully focussed at a strategic time, is more effective than more extensive help given at a period of less emotional accessibility'.

Thus crisis intervention should be a service offered by the social worker in genetics particularly to the parents of the newborn albino. Communication lines should be established with the

Baragwanath Maternity Hospital, the Soweto Health Clinics and other places of birth to enable such parents to obtain social work services at this traumatic time.

(2) Social Group Work

Social group work should be complementary to other methods of counselling. 'If any therapy is, in the long run, to be meaningful and successful, the capacity to associate with others needs to be protected and developed' (Zinberg and Glotfelty, 1968, p. 156). The social worker in human genetics should offer social group work as part of her service, and should apply her skills in this area where and when the need arises.

The two practical alternatives, in the organization of groups relevant to the needs evidenced by the present study, are those of having groups consisting of albinos only, or of albinos and normally pigmented individuals together in equal numbers. The latter method of tackling this approach was suggested by Dr. D. Norris[9] (1974, personal communication). A group consisting of both albinos and normally pigmented individuals would be more representative of society: attitudes and prejudices could then be discussed and reflected in interaction between the albinos and the normal group members. Support from similarly affected individuals might be required by the albinos, so it would be preferable to have similar numbers of affected and unaffected individuals in this type of group. Individuals with similar education and home backgrounds should be selected to take part in such a group, which, to be functional, should not consist of more

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9. Psychiatrist, Tara Hospital, Johannesburg.

than eight subjects in all. The basic aims and concepts of social group-work could then operate, with a contractual understanding of the number of sessions and other practical arrangements.

From the findings of the present study various topics for group discussion are suggested. It seems that attitudes which appear to be conflicting, such as those concerning the marriage of albinos, would provide possible material for group members to consider. Similarly the problem of the death or disappearance of the albino might be handled in a group, rather than with the individual albinos who, denied of the support of fellow sufferers, might not feel free to discuss this matter. A third concern might be that of the health problems suffered by the albino. By group discussion they might discover that their ailments are actually common to the normally pigmented members of the group and not distinctly related to their disorder.

(3) Patient to Patient Counselling

Another method which may be used by the social worker is that of facilitator in 'helper' therapy. Riessman (1965, p. 27) states that helper therapy is an age old therapeutic approach which uses 'people with a problem to help others who have the same problem in more severe form'. Reissman makes the interesting observation that there is a marked current increase in the use of this approach and that 'more attention might well be given the individual who needs the help less, that is, the person who is providing the assistance, because frequently it is he who improves'. It was noted from the results of the present study that very few albinos objected to having albinos as friends. It is the writer's experience, from the genetic counselling clinic, that patients

often express the desire to speak to someone with the same problem. This has, so far, not been attempted with the albinos, and would require a social worker with insight and understanding of the feelings and culture of these patients to determine whether, when and where such patient to patient counselling should take place. Again, individual albinos might benefit from the meeting of their families with other families with an albino member. The sharing of information and discussion of solutions to common problems was found helpful when families with children affected with Down's Syndrome met and confronted one another (Thomberg, 1975) with a social worker as facilitator. Motivation, as well as the similarity in education, background and experience, should be considered when selecting clients who are suitable, and would be helpful to others, or helped by others in this situation.

From discussions at the first International Congress on Patient Counselling (held in Amsterdam in April 1976 and attended by the writer) it would appear that this type of patient to patient counselling is not welcomed by all patients. It is an innovation in therapy and therefore needs further investigation before being offered routinely as an alternative or supplementary approach to the conventional methods of counselling. It is, however, suggested here that several selected subjects in this study might benefit from the support offered by others with the same problem and they should be offered the facility of meeting other albinos.

(4) Family Therapy

Family therapy is a relatively new and fast developing area of concern to the social worker today and it must therefore be a service which is offered to the albino. Some workers consider that the

whole family should be interviewed together, so that family interaction and communication can be improved, thereby facilitating change in the individual. This is seen by these workers to be the only valid approach to the solution of problems relating to personality and social functioning. The situation in the genetic counselling clinic often involves parents and children and sometimes other members of the extended family. The social worker therefore needs skill in this area if the service she if offering is to be comprehensive.

Dr. J. Rubenstein[10] (1976, personal communication) has stated that the focus in family therapy is on altering interpsychic phenomena or personality functioning. In March 1976 Dr. Rubenstein interviewed a family from Soweto in conjunction with the writer, bearing the preliminary findings of the present study in mind. The experience is reported here briefly as an example of interaction with a family in which there are albino members. The family consisted of the two normally pigmented parents together with the two albino sons. The third albino son, who was interviewed in the course of the present study, was absent. The interview illustrated the communications system of the family and various other aspects of the method of family therapy. The father appeared to be the dominant member and verbally stated that he was the 'lion of the family'[11]. Communications were generally channelled through the mother to the children. This system of communicating was accepted within the family and they were considered to be

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10. Professor of Psychiatry, McMasters University, Hamilton,Ontario.

11. Which reflects the pattern of many families in Soweto, see page 36 of the present study.

reasonably well adjusted, both as a family and to the problem of albinism. The fact that the albinos were quite well integrated into the family, and that Dr. Rubenstein considered the adjustment of the family to be good, in that they were coping adequately with their problems, lends more evidence in support of the findings of the present study, which suggested that albinos were as well adjusted as the controls[12].

Although this family was reported to be a healthy, coping family there were others among the young subjects of the present study, for example Doda's[13], who showed signs of needing help. As a further service the social worker should be capable of offering family therapy to families in such need. The appropriate model might be that concerned with structural family therapy, which is 'a body of theory and techniques that approach the individual in his social context. Therapy based on this framework is directed towards changing the organization of the family' (Minuchin, 1974, p. 2). This type of approach to the family might be used in conjunction with genetic counselling where appropriate.

(5) Task-centred Counselling

Finally, an additional service which should be offered by the social worker to the albino and which is, in the opinion of the writer, particularly relevant as a response to findings of the present study is the type of case-work counselling described by Reid as 'task-centred'.

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12. See page 96 of the present study.
13. See page 141 of the present study.

Reid (1975, p. 3) states that

> 'task-centred case-work is a general service model .... in brief, it is a short-term, time-limited form of practice designed to help individuals and families with specific psychosocial problems'.

Reid found that 'a client carries out a specific agreed-on task more effectively when case-work interviews provide guidance for this task'. The social worker and patient would again be expected to reach agreement on the problems to be dealt with and the duration of the service.

An example of the type of problem which could be treated with this model is offered by Doda's case history[14]. He had a specific problem related to employment and the task of obtaining such employment could be worked upon in a counselling situation such as Reid describes. The medical problems that troubled many of the other young albino subjects might also be dealt with through the method of task-centred counselling. The task in this case would be to seek and obtain help from the appropriate source.

In summary, there are several additional methods of counselling which could be carried out by the social worker in a human genetics department and which would provide a responsive service and meet some of the needs, as shown by the results of the present study, of the young albinos in Soweto. These methods are interrelated and are frequently used in conjunction with each other.

9.5.1.3 Referral Service and Environmental Management

The service of referral and environmental management supplements the counselling methods outlined above and is frequently inextri-

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14. See page 142 of the present study.

cably intertwined. Every social worker is required to have an expert knowledge of community resources and the appropriateness of each service. This knowledge is as essential in the setting of the genetic counselling clinic as in all other social work carried out in the field of health (Butrym, 1967). Referrals, in a service involving albinos, would generally be to welfare organizations, employment agencies, and facilities providing the required medical treatment[15].

Where needs cannot be met by the community resources the social worker might be expected to make provision to meet these needs. Such service is often an integral and indivisible part of the research studies of service professionals. As Bartlett (1961, p. 261) wrote 'while some of these studies can be regarded as pure research, others frequently combine the giving of a *service* with the study process'. Environmental management and referral services, which are an integral part of the social worker's functions in her regular day-to-day work, are also important in the course of her research projects.

Kent and Barg (1969, p. 227) observed that very early in their research project it became apparent that the interviewers 'not only were going to uncover problems but were going to be asked to help'. The writer had the same experience and the common needs of the albinos in the present study were, therefore, met both by referrals to appropriate welfare organizations and by specific provision through environmental management. Examples of the latter type of service were the provison of a special

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15. See page 42 of the present study.

protective cream to prevent skin cancer[16], and of protective clothing such as hats and sunglasses to prevent sunburn, to the albino subjects.

9.5.2 Service : Community Aspects

To complement the clinical approach with its various methods of service the social worker in human genetics must also be community orientated. Such involvement in the community has long-term objectives. As Towle (1965, p. xiii) writes, social work practice extends beyond concern with the individual's survival to concern for his rehabilitation, as well as 'the provision of opportunities and conditions that would promote his development, thus hopefully decreasing those social il- - that in the long run burden the taxpayer and threaten the common good'. Furthermore

> 'in defining what the social worker does to achieve the purposes of social work the major focus is not on problems of people or problems of resource systems, but on the interactions between people and resource systems.
>
> (Pincus and Minahan, 1973, p. 15)

One of the social worker's activities, in a service for the albino, is intervention at the appropriate interface and involvement with community functioning at many levels.

An illustration will be presented here to demonstrate how such intervention took place in the course of the present study. The social worker's role was both that of patient advocate and action-researcher. The findings of the present study indicated that there

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16. Special thanks are due here to Dr. Paul Keen of the National Cancer Association who produced a recipe for this anti-actinic cream and to Alex Lipworth and Son who manufactured the cream free of charge.

was a need for accessib'e genetic counselling facilities for the black population of Soweto. Advocacy is one of the responsibilities of

> 'a profession committed to the kind of involvement that sets in motion the helping process and directs it toward the all-encompassing central goal and aspiration of social work, namely, service for the welfare of mankind'.
>
> (McCormick, 1970, p. 8)

Because of this expressed need by the albinos for a service which was not obtainable, the writer, with the backing of the Professor and Head of the Department of Human Genetics, approached the relevant authorities and motivated action to rectify the situation. As a result the first genetic counselling clinic was held at Baragwanath Hospital in March 1975 and this clinic has been held monthly since then.

The social worker in the Department of Human Genetics has also been expected to participate in community organization projects such as the setting up of the Southern African Inherited Disorders Association (S.A.I.D.A.). This association aims to educate the medical, para-medical and lay public, to provide a fellowship for sufferers from genetic disorders and their families and to promote research into human genetics. The social worker is frequently called upon to organize and participate in symposia concerned with genetic disorders. Her other roles in this Association include that of co-ordinator, as well as consultant, activist, and patient advocate. Membership in, and the service of, this Association is open to the albino, as well as to other members of the community who are interested or who have a family history of an inherited disorder.

9.5.3 Teaching

The second major function of the Department of Human Genetics is that of teaching and the social worker offers a service indirectly to the albino in the part she plays. She is frequently called upon to give lectures and talks on genetic counselling and related topics to students from the para-medical professions, to full-time service professionals and to groups of interested members of the lay public. As the teaching responsibilities of the new Department of Human Genetics expand, she will also be required to lecture to medical students. Lectures usually include a discussion of the condition of albinism and the myths and problems that surround it in the black community, and in this way they contribute to a better understanding of the disorder and its associated problems.

Other less formal methods of education are an integral part of all research projects, including the present study. The social worker's role in community education may be that of teacher, expert and/or consultant (Pincus and Minahan, 1973) according to the demands of the situation. For example during the course of the present study the social worker explained the condition of albinism, its etiology and genetics, to community leaders, school staff, health officials and the staff of welfare organizations, thereby again extending this social work service, albeit indirectly, to the albino.

Education through the mass media was also partially explored. Newspapers and magazines have carried articles on albinism, and a videotape of an interview with a family, in which some members

were albinos[17], has been prepared and used with black social workers. Further plans for the more extensive use of the media need to be formulated.

Similarly education through the issue of literature in the form of leaflets and pamphlets needs further expansion. In the course of the present study the State Health Department in collaboration with S.A.I.D.A. produced a booklet entitled 'Genetic disorders and high risk populations'. Albinism is included in this booklet, and a further booklet specifically on albinism is proposed, and will be prepared in due course.

9.5.4 Research

The social worker offers a further service to the albino through her role in the research projects carried out by the department. She is expected to contribute initiative concerning the planning and direction of research, as well as to show competence in research methodology, analysis of data, and the carrying through of a programme of research. As in other departments, such as in Cleveland, the social worker is required to work on manuscripts and assist with 'the preparation and editing of the collaborative research findings' as well as to record 'independent research concerned with attitudes, feelings and behaviour of persons and families with hereditary conditions' (Krush, 1974).

As Evans and Krush (1967, p. 12) state 'unlimited opportunities are at hand for studying individuals, their attitudes, and feelings, towards illness, toward research, and toward affected and unaffected family members ...'. Some of these studies are pure research, but

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17. See page 116 of the present study for a brief description of this interview.

others, such as the present study, have been action-research studies, combining the offering of service, to meet the needs exposed, with the actual research project.

'Participation of social workers in multidiscipline research in the health field assumed importance as a formal activity only recently' (Bartlett, 1961, p. 261). It is a new and vital development in the role of medical social worker and has led to an expanded view by the medical world of the potential contribution of social work. This has been the experience of the writer, who has been requested to provide expertise to other departments of the medical school, in the course of their research studies. This active participation in research has caused a re-evaluation of social work and an acknowledgement that it can competently offer a wider range of activities and service than it has done in the past. According to Polansky (1971, p. 1106), however, 'the researcher of the future will not be occupied full-time, but will be a teacher and an expert practitioner as well'. The young albino will therefore benefit from this broader social work approach, since his needs will not only be defined but provision will be made to meet these needs.

9.6 The Social Work Response to Information gained from the Schedule

The subjects who participated in the present study were asked to respond to two items in the schedule concerning social work. The information they gave is of relevance here[18]. The majority had had no contact with social workers, apart from the writer. The majority also however believed that social workers could provide

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18. See pages 116 to 119 of the present study.

service in many different areas. They saw the role of the social worker as counsellor, provider of material assistance and 'helper of the needy'. The responses ranged through many of the accepted functions of the social worker, from counselling on such specific topics as the parent-child relationship to community organization, such as 'curbing poverty and starvation'.

The albinos stated that the problems on which they would most like counselling were their physical problems and it is hoped that the provision of the new genetic counselling clinic at Baragwanath Hospital will meet this need. Secondly, they requested counselling on 'general' problems and this need should again be met by the provision of a social work service attached to the genetic counselling clinic. Not many albinos requested material assistance, however, but those that did were specifically concerned with bursaries and loans for education and the social worker involved should be aware of this need.

It appears that the social worker's activities as outlined above, together with the services of the genetic counselling clinic experts, should meet the need for genetic counselling which also became evident during the course of the present study.

9.7 Suggestions for Courses on Human Genetics for Social Workers

The social work service to the albino is not complete unless some preparation is made for such service during the training of the social worker.

> 'An expanded knowledge base for social workers containing concepts and information about genetics is imperative in order to develop meaningful team rapport and to enhance services to the client'.
>
> (Schild, 1971, p. 475)

In 1965 Neser and Sudderth were aware of the problem and wrote, referring to genet s and social work, 'the impact of new scientific discoveries in the biophysical sciences has not been reflected in social work education or practice' (p. 22).

The accepted facts, that one in forty children is born with an inherited disorder (Glietenberg, 1967), that one in five children who are admitted to children's hospitals in the developed countries is suffering from an inherited disorder, and, for example, that 1 in 4 000 children in the black community is born with albinism, mean that social workers will increasingly encounter families with . herited disorders. In Johannesburg it has been suggested that the proportion of children admitted with genetic diseases to the local white Childrens Hospital might be as high as 30 per cent (Jenkins *et al.*, 1973).

Nevertheless admittedly there is the problem of 'the delineation of the genetic theory and knowledge that should be included both in generic social work education and in the specific setting of practice' (Schild, 1971, p. 475). It is suggested here, that from the experience of the writer, knowledge in certain areas would provide a sound basis to enable social workers in all fields of practice to provide a service of enhanced helpfulness to clients with genetic disorders. Broadly a course on genetics for social workers should include:

(1) A detailed study of the modes of inheritance, an understanding of which is basic to genetic counselling.

(2) A description and explanation of the incidence and nature of the genetic disorders which are common in the different population groups in South Africa (for example this would include albinism).

(3) A study of the psychosocial implications of genetic disorders and their impact on the individual, the family and the community.

(4) An analysis and discussion of genetic counselling techniques and the social worker's role in a genetic counselling clinic.

(5) Practical experience in counselling families with inherited disorders and in participating in research procedures in the Department of Human Genetics.

Human Genetics falls in the health field and an important factor in facilitating communication between medical social workers and doctors is an 'intelligent interest in, and a sound grasp of, the medical facts in each situation on the part of the social worker' (Butrym, 1967, p. 9). It is therefore important, from many points of view, that a course in human genetics as outlined above should be offered as part of the training in medical social work which all social work students receive. As Schild (1971, p. 476) states 'the social worker in genetics is carrying out the traditional role of the medical social worker, utilizing generic social work skills and techniques and an augmented knowledge about inheritance theory and information'. Some of this knowledge will be obtained during in-service training, but a broad background should be provided at the undergraduate level.

9.8 Summary and Conclusion

The social worker's service to the albino should include activity in each of the fields for which her training equips her i.e. case-work, group-work, community organization, administration, research and teaching. In summary her service in the present context is expected to have clinical aspects which particularly include: participation in genetic counselling, the offering of the services of crisis counselling and social group-work, family

therapy and task centred counselling and the facilitating of patient-to-patient counselling. Her service is expected to involve environmental management and referrals, and to have far reaching community aspects involving community organization and education. Then she is also required to fulfil roles in teaching and research.

The findings of the present study have stimulated provision of facilities to meet some of the needs of the albinos in Soweto due partly to the writer's dual role as researcher and social worker. There is still however much that remains to be implemented if the quality of service to the albino is to be improved.

CHAPTER 10

DISCUSSION AND CONCLUSIONS

10.1 Introduction

The foregoing Chapters of this dissertation report on a study of some features of the adjustment of a group of young albinos, in comparison with a group of young normally pigmented control subjects, and some aspects of the attitudes of both groups towards albinism. Some problems and needs of the albinos have been determined, and the social work service in the Department of Human Genetics, which deals with such problems of a genetic nature, has been discussed.

It remains therefore to discuss the findings with reference to the aims of the study, to the background i.e. Soweto and to the other studies on albinism recorded in the literature, and to draw conclusions from this discussion. Then suggestions must be made regarding areas which require further research, regarding action in the several fields peripheral to the study and regarding the social worker's role in the implementation of the action that is required in her field of service. Finally some broad recommendations which result from the findings of the present study will be offered.

10.2 Discussion of Findings

The discussion of the findings will be considered under two headings: firstly, the general findings resulting from the comparative study of the albino and control subjects in respect of their adjustment levels and their attitudes towards albinism; and secondly the specific findings in various problem areas.

10.2.1 General Findings

The first general finding of the present exploratory comparative study was that, according to the statistical analysis of the responses of the subjects to the twenty schedule items concerned with adjustment, the subjects in the experimental albino group appeared to be as well adjusted as the subjects in the matched control group. There was no significant difference between the groups on overall scores ($p > 0.90$); or between the Higher Primary School subjects ($p > 0.50$), the High School subjects ($p > 0.20$), the Drop-out subjects ($p > 0.90$), or the males ($p > 0.20$) or females ($p > 0.20$) in the albino and control groups.

These findings are interesting since one might have expected that albinos would not be as well adjusted as normally pigmented individuals, because of their being so obviously and strikingly different, in terms of skin colour in the black community.

> '"To be different" is to be "set apart", which, in the language of interpersonal relations may signify rejection .... Many writers have also attributed the rejection of a person with a disability to the fact that he is *different*. "No one wants to be different" is accepted as an obvious law of man'.
>
> (Wright, 1960, p. 262)

Not only are they different, but they have white skins, in a country where skin colour was, at the time of the study, associated with special privileges, increased opportunities and better standards of living. One might have again assumed that this would cause conflict in the albino resulting in some maladjustment.

Another problem which might have been thought to produce a difference in the adjustment levels of albinos and controls was the possible marginal status of the albinos. If a marginal situation is defined as 'non-membership or incomplete membership of a

co-existing privileged group into which entry is barred' (Mann, 1957, p. 40), then the albino appears to be in a marginal situation. With his white skin he seems to be between the white group, which distributes privileges along colour lines, and from whose membership he is barred, and the black subordinate and underprivileged group, which is his 'reference group'. The albino however does not identify himself with the dominant group and therefore is not 'likely to develop marginal personality traits' (Dickie-Clark, 1966, p. 20). Neither is he in a culture conflict situation and he seems to consider himself, as most of the normal controls considered him, to be 'a black person just like any other black person' (statement of one of the subjects). Suggestions that the albino is in a marginal situation may therefore be invalid, although further research might throw light on this matter.

Other studies also led the writer to expect that the albinos might have adjustment problems. Beckham (1946)[1] found, from his study of the social histories of forty-two negro albinos in the U.S.A., that they had some problems, particularly those of family and personal adjustment. Similarly Stewart and Keeler (1965)[2] studied six Cuna Indian albinos and found them to be emotionally immature and psychologically less healthy than the six normally pigmented controls with whom they were compared. Beckham's study was not scientifically designed, he did not have a control group and his conclusions appear to be impressions only, while Stewart and Keeler studied only six albino subjects and six controls, and these subjects were submitted to stress by being flown from their

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1. See page 21 of the present study.
2. See page 26 of the present study.

native islands to a large American city for study. The general findings of the present study are not in agreement with those indicated by these studies, nevertheless the local unstable setting of the stuoy possibly means that the findings are not comparable.

Finally one might have expected that the albinos would show signs of maladjustment, when compared with the controls, because of the Zulu word 'Inkau', or monkey, which is commonly used to describe albinos in Soweto (Kromberg and Jenkins, 1976).

Having briefly discussed the unexpected and surprising nature of the findings however, the writer will proceed to outline the short-comings of the study and the reasons why the study might have produced such results. Five factors seem to be incriminated : the possibility of unreliable responses, the shallowness and brevity of the schedule, the insidous problems of Soweto, of the urbanization process and of adolescence.

(1) The first factor which might have produced the results is that of unreliable responses. Castle *et al.* (1976) found when studying a black group for emotional stress in Rhodesia that there were difficulties involved. The scores of their black subjects indicated 'that, compared with Whites, Blacks are more strongly influenced by an attempt to conform to the socially acceptable response' (p. 1146). Similarly Biesheuvel (1958, p. 170) stated that

> 'The problem of ensuring that verbalized attitudes will throw light on behaviour in real-life situations is aggravated in African studies by the difficulty in obtaining genuine responses'.

The interviewers in the present study were asked to probe, and use the Why's appended to certain items, in an effort to deal with this problem.

(2) The methodology of the study required that a schedule be constructed to test adjustment and attitudes. It is possible that the items selected for the schedule were not sufficiently discriminating, due to the necessity of using simple concepts that could easily be understood and translated. Similarly the schedule might have been too shallow or too brief to discern any psychological or adjustment differences between the groups. Nevertheless, as Howe (1975, p. 28) writes, the majority of social science research projects are based upon interviews and questionnaires, and 'a similar assertion could probably be made about social work research'. Therefore, not withstanding all the difficulties involved in administering a schedule in an interview, this means is still frequently used and valuable data are collected.

The cultural barrier between the writer and the subjects might too have presented problems. This difficulty was however partly dealt with by involving a black clinical psychologist and experienced black interviewers in the formation of the items for the schedule, and by using the latter to carry out all the interviewing.

(3) The multiple problems of young black people living in Soweto[3] might be a further factor which influenced the results. These insidious problems are all invasive and might have obscured any differences that would otherwise have been shown up by the methods adopted for the present study. As Manganyi (1974, p. 923) states, concerning black residential areas bordering on white cities,

> 'the basic characteristic of these satellite communities is that in important respects they are neither urban nor industrial since their economic viability is entirely dependent on the white cities'.

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3. See page 36 of the present study.

These communities therefore have certain psychosocial characteristics: a high rate of morbidity and social pathology; child rearing practices that are non-traditional and non-supportive; and absence of community support during periods of stress. Such characteristics alone could produce problems so glaring that the personal problems of the albino might pale into insignificance. The confusion, disorder, and turmoil which have erupted in Soweto[4] in 1976 is an indication of the magnitude of these problems.

(4) The urban crisis itself creates problems so extensive that they too could possibly have contributed to the results of the present study.

> 'Man's folkways, mores and culture were, for the most part, developed in rural settings to solve the needs of a rural society. Man now finds himself living in great metropolitan regions largely without an urban religion, urban philosophy or urban family patterns'.
>
> (McDonagh and Simpson, 1969, p. 5)

This urbanization process may be all the more traumatic for the local black population in Soweto who have only been exposed to city life and industrialization since the turn of the century. Mitchell (1969, p. 10) suggests that one of the most striking manifestations of urban change and stress is 'seen in the current impact on the Negro and his search for identity'. This may well be true too of the local black person, under the pressure of the problems inherent in the local rapid urbanization process.

(5) Finally the results and subsequent findings of the present study may have been affected by the possibility of the general turmoil of adolescence. As La Barre (1969, p. 23) writes 'If there

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4. See page 46 of the present study.

is dependent childhood versus protective adulthood, if there is culture and the learning of it, then adolescence must be a major focus of stress'. On the other hand stress and change are not rare states, they are the 'very stuff and nature of living existence'; each successive step in life evokes a new adaptation and this may not be specific to adolescence. The effort 'to change oneself, redefine oneself or reform oneself does not cease with the arrival of adulthood' (Keniston, 1969, p. 108). It may therefore be that this factor is invalid as source of influence on the findings of the present study.

Some or all of these five factors, or even other unrecognized factors, may have influenced the findings of the present study. The general finding, however, that the albino is as well adjusted as the control, is a finding which is supported partially by similar findings in other studies. Barnicot (1952)[5] stated that there appeared to be no discrimination against twenty-one albinos whom he studied in Nigeria. Woolf and Grant (1962)[6] found that amongst the Hopi Indians the albinos were viewed as other individuals with congenital defects and were well integrated into the community. Shatto and Keeler (1971, p. 11) studied the Cuna Indian albinos and found that they were ambitious students, seeking better education and 'preparing themselves to fit into a more highly developed society'.

A similar study to the present study was carried out by Kumar *et al.* (1976, p. 859) on black adolescents with sickle cell anaemia[7]

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5. See page 22 of the present study.
6. See page 24 of the present study.
7. A rare recessive genetic disorder of the Haemoglobin resulting in a serious anaemia.

in Los Angeles. The authors aimed to explore 'the relationship between a patient's chronic physical disease on one hand and his problems of emotionality and psychosocial adjustment on the other'. They stated that anxiety, self-concept and adjustment processes should be empirically studied 'in order that more comprehensive care can be made available to children with sickle cell disease' (p. 860). They found that although youngsters with the disease did not differ from a peer group of normal school-children in personal, social and total adjustment, and that this was possibly due to consistent family support and health care, they did nevertheless require enhancing of their self-concept. Sickle cell disease is, however, a serious and frequently fatal disease. It is for this reason only comparable with albinism if both groups give equal weight to their disease, which is improbable. The serious nature of the disease could itself lead to better family support resulting in good general adjustment.

The albinos in the present study might too have shown a similar adjustment to the control group because of the support of their families (Kromberg and Jenkins, in preparation)[8]. Their level of adjustment, however, might also be affected by the positive attitudes of the community which were shown by the findings of the present study[9].

The findings resulting from the clinical psychologists' assessments of the albinos and controls responses to the 'Why's' appended to fourteen adjustment items merits comment. The clinical psychologists judged the albino group to be better adjusted than the control

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8. See page 27 of the present study.
9. See page 107 of the present study.

group ($p < 0.05$)[10]. Manganyi *et al.* (1974) found that the albinos in their study had a significantly less diffuse body boundary differentiation than the controls, and this may be another piece of evidence in support of the better adjustment level shown by the albinos here. According to the clinical psychologists the difference lay in the scores of the females in the two groups. The albino females showed a markedly better adjustment than the control females ($p < 0.01$), this was a trend also seen in the females in the Higher Primary and Drop-out groups, but the numbers[11] were too few for tests of the significance of the differences to be calculated. That the females should show this tendency is interesting; again it is possibly a result of the protectiveness and support of their families[12]; alternatively it may be that females at the time of adolescence generally show better adjustment than males. An important reason for this difference, however, may be that the control females show such positive attitudes towards albinism; this could contribute to the good adjustment shown by their albino female peer group.

The second major finding was concerned with the attitudes of the two groups towards albinism. The results of the present study showed that there were no significant differences between the two groups on overall scores for attitudes to albinism ($p > 0.20$)[13]. The two groups of females were more alike in their attitudes than the males. The control males showed a significantly less positive

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10. See page 103 of the present study.
11. See page 99 of the present study.
12. See page 28 of the present study.
13. See page 107 of the present study.

attitude than the albino males ($p < 0.05$), which may indicate a tendency for the normal males to be less able to accept a person with a physical defect than the normal females. This would be an interesting topic for further research. These findings are however also subject to the limiting factors discussed in regard to the adjustment levels[14].

In summary, then, the albino group showed no significant difference, in comparison with the control group, on adjustment as measured in the present study. This finding might be actual, it might be a result of the positive attitudes of the community, as indicated by the control group, or it might be consistent with the very complex social and psychological environment in which the subjects of this study are living.

10.2.2 Specific Findings

According to the overall scores of the two groups in the study, the adjustment patterns were similar, and the attitudes towards albinism were positive. There were however a few schedule items which brought out significant differences between the two groups and indicated some of the problems and needs of the albinos. These specific findings will be discussed in five areas: marriage, employment, death, lack of knowledge with regard to albinism, and physical and psychological problems.

(1) The first problem to be discussed is that of the marriage of albinos. Both the groups studied appeared to approve of marriage between albinos and non-albinos. The actions of the local black people, however, do not match their attitudes as stated here.

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14. See pages 182 to 185 of the present study.

For example of the twenty albino women of marriageable age known to the writer only five are married, and of the twenty-eight albino males only a further five are married. It is accepted that attitudes inferred from what a person says about [illegible]titude object and the way he feels about it, might not be consis[illegible]th how he behaves when confronted with an actual situation.

> 'Attitudes involve what people *think* about, *feel* about, and how they would *like to behave* toward 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 consequences of the behaviour*'.
>
> (Triandis, 1971, p. 14)

Discrepancies between verbal attitudes and overt behaviour were observed by Linn (1965, p. 353) and he stated that the relationship between attitude and behaviour is 'seen to be a function of the level of social involvement with the attitude objects as well as the amount of prior experience with it'. Although the control subjects were chosen from a school which was attended by at least one albino, they presumably have only minimal exposure to the problem merely because there are so few albinos in the community, and therefore there is the likelihood that their attitudes, particularly in such sensitive areas as marriage, may not be related to their behaviour.

Possibly there was one important item that was omitted from the schedule i.e. 'Would you marry an albino?' This item was considered, at the time the schedule was constructed, to have too many emotional overtones to elicit truthful responses, it might nevertheless have produced some valuable and interesting information. The item 'Would you allow your child to marry an albino' was

included and the majority of responses elicited were favourable.

Barnicot (1952) observed that only thirteen of the twenty-one albinos in his survey[15] were married, and Vallois (1950) found that in certain tribes in the French Cameroons there were restrictions on the marriage of albinos. Also among the Balinese, sexual relations with albinos, idiots, lepers and in general the sick and the deformed, are tabooed (Wright, 1960). Stewart and Keeler (1965) concluded from their study[16] that the male albinos showed a passive dependent feminine orientation with little interest in the opposite sex. These observations support the impression of the writer that, although attitudes towards marriage were positive in the present study, there is some barrier that causes albinos to marry only rarely. The study showed no evidence of tribal customs or beliefs relating to the marriage of albinos, so this barrier requires clarification. Further investigation in this area is necessary for a fuller understanding of the problem.

(2) The second problem was that of employment and the responses to the relevant item showed significant differences between the groups. The young albinos seem to consider that the obtaining of suitable employment would be a serious problem affecting them in the future. The majority of those in the study had never worked so there was some factor, other than experience, operating to formulate this attitude in the albinos. It is possible that this attitude relates to the local situation, where the opportunities of employment are limited and many black workers are employed in situations where manual labour is required, and

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15. See page 22 of the present study.
16. See page 26 of the present study.

where exposure to the elements might occur. The albinos might consider this a problem, knowing that exposure to the sun, being detrimental to their well-being and resulting in discomfort to their eyes and skin, will cause their opportunities in the open labour market to be even further limited. Another problem here may be the projected attitudes of the employers, the majority of whom will be white. According to the schedule responses the albino believes he is not unlike the black controls in many attitudes, personality characteristics and beliefs, and that he is generally accepted by the black community. The responses of the black control group reinforced that belief. What the albino thinks of the attitudes of the white community, however, has not been investigated, and it is possible that he considers these to be more negative[17] and therefore assumes that this will also lead to difficulty in obtaining employment.

Barnicot (1952) had the impression from his study[18] that albinos were not markedly handicapped with regard to occupation. Shatto and Keeler (1971) studied the Cuna Indian albinos on the San Blas Islands and asked 'Does an individual's physical handicap automatically imply that he will also experience an economic handicap?' The authors found that in the agricultural society of the past the albinos endured an economic as well as a physical handicap. In a developing community, however, 'where greater specialization occurs, the albinos appear to experience much less of an economic handicap than in the past'. Nevertheless the

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17. Anecdotal evidence suggests that some white employers do have negative attitudes towards albinos. For example one medical practitioner when examining applicants for engagement on the mines was requested to reject albinos.

18. See page 22 of the present study.

authors state, concerning their albino subjects,

> 'some withdraw completely, do not work, and do not share in any community activities. Those who are employed do not exhibit any sense of inferiority from their inability to do all jobs well, but rather they appear to concentrate on excelling in one area'.
>
> (Shatto and Keeler, 1971, p. 12)

The employment situation for the albino therefore does not appear to be as hopeless as the local young albino might think. Further research, together with action, counselling, and education of the public, particularly employers, in the local situation appears to be necessary.

(3) The third problem is that of death. Nearly half the control group believed that albinos do not die a natural death. In the writer's experience this is a belief which is evident at all levels of the black community. To cite one example, early in the study a nursing sister, with whom the writer was discussing albinism, asked whether albinos die in natural circumstances. When the writer requested a reason for this question she explained that she had neve seen an albino die and therefore wondered where, or how they died. The albinos are aware that there is a widely held belief in the community that albinos do not die like others die and this awareness may lead to some interesting psychological dilemmas, many of which may not have been properly resolved and may be causing discomfort in the albino. If there is discomfort present it may be linked with the finding of the present study, that albinos claimed to have more physical problems than the controls, particularly those problems which were unrelated to their condition. Many albinos themselves indicated that there might be some mystery surrounding their deaths, but they were not

asked to amplify their statements and much more information is required if the consequences of these feelings on their personality functioning are to be defined and clarified.

Nevertheless Fulton (1965, p. 80) states, referring to a study carried out by Adlerstein and Alexander on the affective response to death in children and young adolescents, that 'death has a greater emotional significance for people with less stable ego structures than for those with an adequate conception of themselves'. This may apply to the young albino as well, and may determine the way in which he handles the knowledge of the prevalent belief concerning his death. The topic is a very interesting one for further psychologically orientated research studies.

(4) The fourth problem which became evident was the lack of knowledge in both groups concerning albinism, its etiology and mode of inheritance. Genetics is a relatively new field and even in highly developed communities there is little understanding of the basic concepts involved in the modes of inheritance, and of which of the congenital disorders, in the community, are inherited. Various 'old wives' tales still come to the fore as explanations for the birth of a defective child. Education is, however, advancing and there are now, in the Biology textbooks, used in high schools in South Africa, references to genetics which include not only an outline of Mendel's laws, but also a few brief comments on human genetic disorders and their modes of inheritance (Austoker and Cheeseman, 1971). The finding that the albinos themselves knew very little about their condition emphasizes the need for improved and expanded genetic counselling facilities for the black community.

(5) The fifth problem that was exposed was the albinos' concern about physical ailments. Certain of these can be associated with the disorder of pigmentation which the albinos have. There is no doubt that the disorder leads to a skin type which is extremely sensitive to the sun, and requires protection, and to eyes which often need to remain half closed in bright light and require lenses at an early age (Fonda *et al.*, 1971). The albino group however complained of many physical problems apart from those concerned with the skin and eyes. It is possible that their complaints of headaches may be justified and that good medical treatment, together with preventive health education, by attention to the eyes and skin problems may minimize these headaches. It is also possible, however, that these headaches are a psychosomatic symptom of some deeper neurosis which has not been exposed by the limited depth and scope of this study.

> 'Psychosomatic manifestations like any symptom, signify for the individual some failure of more adaptive coping mechanisms ... such symptoms probably occur concomitantly with repression or suppression of affects when an individual is physiologically vulnerable or the affects are unusually primitive, strong or habitual'.
>
> (Nelsen, 1969, p. 581)

Whether or not there are actually symptoms of a psychosomatic nature in the albino's complaints of physical problems is still to be clarified, and if they are present then the suppressed affect to which they might be related needs further study.

The number of 'troubles' reported by the albino group was also significantly higher than the number reported by the control group. Again the albino responses included many 'troubles' which were related to health complaints. As Vernon (1964, p. 269) 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 therefore that the albinos were expressing psychological problems which the items used in this scale were too few and too superficial to detect, and further investigation may be indicated in this area.

Although the albino showed excessive concern over physical problem the responses to the item concerning satisfaction with one's appearance were of interest. Significantly fewer of the albinos than the controls were ashamed of their appearance ($p < 0.01$)[19]. This finding may be connected with the fact that in South Africa at the time of the study skin colour was associated with special privileges. Alternatively, this finding may be caused by an unexpressed view of the albino as, in some way, a special person, and with Shatto and Keeler's (1971, p. 11) finding that albinos, among the San Blas Indians, are 'believed to possess supernatural powers - "to sin less and to be on better terms with Tiolele, the Sungod"'. This latter association would tie up with the finding in the present study that albinos had significantly more interest than the controls in religious activities. A third possibility is that the albinos show less shame concerning their appearance because they experience a less diffuse body boundary differentiation as shown by Manganyi *et al.'s* (1974) study. Finally it is possible that the albino relies on the defence mechanism of denial, as Stewart and Keeler's (1965) study showed[20]. These possibilities all require further exploratory research to

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19. See page 101 of the present study.
20. See page 26 of the present study.

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determine whether or not the albinos do have an enhanced self-concept, and if they do, to examine the reasons for this phenomenon.

In summary then the specific findings show that the young albinos, although in general as well adjusted as the normally pigmented controls, did have several specific problems. These problems were associated with marriage, employment, the common belief concerning death and the lack of knowledge concerning the genetics of their condition. There was also evidence of physical problems, some of which resulted from the condition and, others which were not directly connected and could be said to be psychosomatic, and might indicate psychological problems which were not exposed in the present study. The problem of self-concept was investigated only briefly and whether or not the albino has a better self-image than the non-albino is still debatable.

10.3 Conclusions relating to the Aims of the Study

The conclusions relating to the aims of the present study may be stated as follows:

(1) The first aim was to study the comparative level of adjustment of the young albino. It appears from the results that the albino subjects achieved the same level of adjustment as the controls, but that they claimed to have more physical problems, particularly those which were associated with their condition. Whether or not the whole community of young black people, including the albinos, in Soweto are poorly adjusted is a matter of conjecture. Also whether superficial responses of the subjects, the urbanization process or the turmoil of youth contributed to this result is unclear. Nevertheless within the limitations of the study and against the background of Soweto, the conclusions are that the

albino youth appear, in regard to most features of their adjustment, to be as well-adjusted as the matched controls.

(2) The second aim was to compare the attitudes of a normally pigmented control group and an albino group with regard to albinism. The results showed that the attitudes of the control group were very similar to those of the albino group and were generally positive; the attitudes of the control males however were less positive than those of the albino males. The finding of positive attitudes indicates that the albinos were reasonably well accepted by the community, as represented by the sample studied here, and this factor may contribute toward the adjustment level of the albinos.

(3) The third aim was, on the basis of the data obtained from (1) and (2) above, to make suggestions for a social work service relating to albinos. During the course of the study the albinos expressed the need for counselling concerning their physical needs and particularly concerning the myths and misconceptions relating to their disorder and its genetic nature. The social work service most appropriate to respond to these needs is based in the Department of Human Genetics. The service of this Department was examined and was seen to involve not only genetic counselling but also additional services. These latter services were specifically the responsibility of the social worker, and included crisis counselling, social group work, facilitating patient to patient counselling, family therapy, task-centred counselling, environmental management and referral, community service, as well as teaching and research. All the facets of this service could be used to the benefit of the albino, and suggestions for improvements and

expansion to meet the needs as exposed in the present study were made.

10.4 Suggestions for further Research

The study reported here was an exploratory study which aimed to collect information in three areas, viz. the comparative adjustment of the two groups of subjects, the attitudes of both, and clarification of client-centred and problem-focused social work action. The scope of the study was therefore limited, but nevertheless the findings indicate some general directions which future research might take.

Firstly, it would be very interesting to discover the extent to which living in a society such as exists in South Africa, where there is tremendous importance attached to skin colour, affects the albino. A comparative study might be made, for example, of Negro albinos living in New York with those living in South Africa; or of Caucasoid albinos, who show little skin colour difference from their peer group, with Negro albinos who show a great skin colour difference from their peer group. Also further research might be directed towards an investigation of whether or not the albino actually considers himself a marginal man, and if so, whether this is more marked in a community where racial discrimination operates or in a community where the differences between the races are submerged.

Secondly, investigation in the area of marriage is indicated. Questions that might be considered are concerned with why it is that the black community verbally approve of marriage with albinos but do not behave according to these expressed attitudes; and whether there are unexpressed beliefs or taboos concerning marriage with albinos.

Thirdly, action-orientated research is required into the employment needs and problems of the albino. Attitudes of employers should be investigated and any prejudice towards albinos should be examined, so that solutions to this problem might be proposed, and opportunities for employment for albinos might be developed.

Fourthly, the common misconceptions concerning the albino's death need careful study. Whether or not these myths are associated with other cultural attitudes towards life and death, and health and sickness, in the black community, is a question which merits consideration. Also whether or not other specific members of the community are believed to die in mysterious circumstances would contribute to an understanding of this problem. Again does the 'setting apart' of the albino in this way also give him special status in religious activities and in regard to the facilitation of divine communication? The origin, history and background of this belief might be studied in the folklore of the people. At the same time connections between physical and psychosomatic ailments and the death belief might be explored, since it is possible that the pain tolerance threshold may be reduced due to the doubt, even in the albino himself, that he will die a natural death, and that he might therefore be supernatural. The psychological side-effects of this belief on the personality functioning of the albino required closer examination.

Fifthly, the physical and psychosomatic problems of the albino should be studied. Whether these problems are necessarily attached to the condition or whether they result from deep-seated psychological problems should be determined. The matter of the self-concept of the albino is also an interesting field for further psychological investigation.

Lastly, research is required into the methods used in genetic counselling and in the communicating of information to the family with a genetic disorder. Concepts such as recessive inheritance are difficult to explain and a study of various methods and visual aids is required, so that better methods of communicating this new material might be formulated. Similarly, the concept of the gene itself is not easy to understand and some simple method of describing and explaining this to unsophisticated peoples should be explored.

10.5 Implications of the Study for Future Action

Future action resulting as a response to this study is required in several professional areas:

Firstly, the development and improvement of medical services is required. To assist the albino with his predominantly physical problems, and to reduce his discomfort, medical expertise from dermatologists and opthalmologists is needed. The experts should have an understanding of the albino as a person and of his problems and needs, some of which have been outlined in the present study, in order to treat him in the most relevant way. The medical geneticists need to be alerted to the albino's ignorance of the genetics of his condition, and to the need to provide further services for genetic counselling for the albino.

Secondly, clinical psychologists may be required to assist the albino who has deep-seated problems of personality functioning and to investigate the psychological side-effects of albinism. There are very few, if any, black clinical psychologists in South Africa to-day and the training of such experts would be another necessity of future action, if adequate services are to be provided.

Thirdly, action in the form of research into cultural beliefs might be instigated by the anthropologists. They might also be alerted to the need for awareness of observations, from cultural and folklore studies, which might relate to albinism.

Fourthly, action is required of social workers, nurses, health visitors, health educators, and teachers, all of whom have regular contact with the public. These professionals can communicate a new awareness of genetic disorders and their etiology, and, in this way, dispel myths and misconceptions which complicate the understanding and acceptance of the condition in both the affected family and the community.

Lastly, action is required by social workers in all the areas of their professional functioning. They are required to absorb information, which should be provided in undergraduate courses, on human genetics, and on the psychosocial problems that surround genetic disorders. They will then be able to undertake the counselling of the albino and his family with insight and understanding. They will also be capable of action regarding the organizing of group services for albinos, and of participation in the education of the community, so that the ultimate goal of improving the quality of life for the albino might be achieved.

10.6 The Social Worker's Role in the Implementation of Action Required by the Present Study

According to Bartlett (1961) the social worker in the medical field has two major contributions to offer, and these are vital as bases for the implementation of plans into action. These two contributions are related and often intertwined, but might be postulated as follows:

(1) 'To develop awareness of the significance, and understanding of the nature of the psychosocial components - the social needs - which are a constant element in the central problem or condition;

(2) To participate actively in the provision of adequate services to meet these social needs, either by giving direct services or by influencing the development of specific programs and of social policy as a basis for future program'.

(Bartlett, 1961, p. 50)

The social worker in the health field, and specifically in the rapidly expanding genetic section of the health field, has a special responsibility to make the psychosocial approach operative. As Bartlett adds

> 'the social worker who has helped a young intern or nurse to greater awareness of the social stress in the situation of one of their patients, to better understanding of its nature, and to acceptance of responsibility for doing something about it has done a service as important as rendering a casework service directly to that patient.
>
> (Bartlett, 1961, p. 51)

The social worker in the Department of Human Genetics fulfils the same professional activities as the social worker in other medical fields, with some additional responsibilities, particularly in the field of research. She is involved with administration and planning, services to patients and their families, educational activities. consultation, as well as having the opportunity to conduct research into 'psycho-socio-economic problems and concurrent investigations of the psychosocial implications of hereditary disorders' (Evans and Krush, 1967, p. 11). Her 'knowledge of case work, interviewing techniques, understanding of human behaviour, and working in a team relationship' (Krush, 1974, personal communication) is valuable in many situations.

The social worker in genetics then might be expected to

implement recommendations resulting from research projects such as this. She might be expected through her administrative and planning duties to organize better genetic counselling services for the black community. She might be expected through her service responsibility to provide or to stimulate the provision of case-work and social group-work facilities, or a smooth referral system to such appropriate available facilities. She might be expected, through her role as educator, to publicize information on albinism through the written and spoken word. She might within her functioning as a consultant, be expected to keep the medical and paramedical professionals informed on psychosocial research and its implications for daily problems with patients with genetic disorders. Finally within her role as researcher, she might be expected to fulfil the demands for further investigation into some of the features of the adjustment of albinos which have been shown to be problematic during the course of the present study.

10.7 Recommendations

Recommendations resulting from the data collected in the course of the present study may be summarized as follows:-

(1) Services for genetic counselling for the black community need improvement and expansion. The inclusion of a medical social worker trained in human genetics in the medical team, in the genetic counselling clinic, is important if the quality of service found elsewhere in the world is to be provided in South Africa.

(2) Courses on human genetics, the psychosocial aspects of genetic disorders, and genetic counselling, should be included in the curriculum of undergraduate students of social work.

(3) The education of the community, medical, paramedical and lay, through mass media, concerning the nature of albinism and its inheritance is required.

(4) Research, with the ultimate aim of facilitating planning related to improving the quality of life for the albino, is required, particularly in the areas of marginality, marriage, death, employment and the communication of genetic information. Wherever possible this research should be action-orientated.

10.8 Summary and Conclusion

The main aim of the present study was to investigate some features of the adjustment of the young albino in Soweto. Further the investigations aimed to explore some of the prevailing attitudes of youth in Soweto towards albinism and to outline a social work service for the albino.

The results suggested that the albinos' level of adjustment was similar to that of the controls. This finding might show that the albinos are not severely handicapped by their condition, or it might indicate that there are various complex psychosocial factors operating in the community in which the subjects live, which obscure psychological differences between the albinos and non-albinos.

The attitudes towards the albinos were positive and this finding, unless it too is influenced by the multiple problems of the community, would tend to lend support to the finding that the albinos attained the same level of adjustment as the controls.

Certain specific problems were however uncovered during the study. On the basis of data obtained from the study of these problems and the responses to the items on adjustment and attitudes, suggestions were made for a social work service relating to albinos. This service is integrated into the Department of Human Genetics and the genetic counselling services provided by that Department.

Recommendations have been made and if these are implemented the albino should in the future be enabled to cope more adequately with

the specific problems that confront him, and the social worker, who is in the position to help, should be enabled to ease the burden, resulting from the presence of albinism, for the individual, family and community.

If, as Towle (1965, p. xvii) writes,

> 'the institutions and agencies established to serve mankind are not to lose identity with people, becoming self-perpetuating and rigidly unsuited to human needs, then they must continuously have the breath of human life breathed into them'. This breath of life is 'the basic understanding of individuals, a growing comprehension of their common needs, their behaviour motivations, and the factors and forces that shape men to be primitive or civilized in their strivings'.

The present study was a modest effort to provide a 'breath of human life', in the form of a limited understanding of the young albino in Soweto, his adjustment and needs, so that the established institutions might become more suited to his requirements and might not lose identity with the people whom they serve.

APPENDIX A

IDENTIFYING INFORMATION REQUIRED IN SECTION I OF THE SCHEDULE

For the final form of the Schedule these Items were:

1. Name
2. Address
3. Albino/control
4. Date of birth and sex
5. Occupation
6. Income
7. Education
8. Religion
9. Occupational History
10. Arrests
11. Changes of residence
12. Medical History
13. Social work agencies involved
14. Interests

For the pilot study the details required were reduced to name, address, age, school standard, language, date of birth, sex, name of school and tribal origin.

APPENDIX B

COMMON INDICATORS OF MALADJUSTMENT IN YOUNG PEOPLE

Woodruff (1948) lists common indicators of maladjustment in young people, and divides them into two groups as follows:

I. Symptoms indicative of unsolved problems.

(a) Casual overt behaviour : for example frowning, blinking, nail biting, constant moving, muscle twitching.

(b) Intensive or explosive reactions : for example sudden frights, anxieties, fears, hysterical laughing or crying, violent arguing.

(c) Exhibitionism:

(1) Aggression : eg. teasing, bullying, threatening others, blaming others for troubles.

(2) Self-display : eg. showing off, attempts to be centre of activity, exaggeration.

(d) Preoccupation : eg. use of excessive denial, worry over failures, day-dreaming.

(e) Withdrawal : eg. excessive reading, avoiding others, being as inconspicuous as possible.

(f) Minor physical dysfunction : eg. fatigue, aches and pains, frequent headaches, insomnia, digestive disorders.

II. Symptoms of Immaturity

(a) Poor motivational health : eg. constant seeking of advice, difficulty making choices.

(b) Fixations or delays in normal progress : eg. inability to make friends, dependence on parental authority in place of recognizing other authorities and facts.

APPENDIX C

ITEM SELECTION FOR SECTION II OF THE SCHEDULE

The item selection for the sub-scales on adjustment in Section II of the schedule appear in Tables 1, 2 and 3.

TABLE 1

ITEM SELECTION FOR INTERPERSONAL SUB-SCALE OF SECTION II OF THE SCHEDULE

	Item	Source
1.	Do you like to be the centre of everyone's attention?	Woodruff
2.	Do you find it difficult to speak in class?	Bell, S.R.A.*
3.	Do you feel like running away from home?	Bell, S.R.A.
4.	Do you feel happy with your brothers and sisters?	Bell, S.R.A.
5	Do you feel you don't belong in your family?	S.R.A.
6.	Do you make friends easily?	Woodruff
7.	Do you think others treat you unfairly?	Woodruff
8.	Do you get on well with your relatives?	Woodruff
9.	Do you blame others for your troubles?	Woodruff
10.	Have your relations with your mother usually been pleasant?	Bell
11.	Have your relations with your father usually been pleasant?	Bell
12.	Do you avoid other people?	Woodruff

* Science Research Associates Inventory.

TABLE 2

ITEM SELECTION FOR EMOTIONAL SUB-SCALE

OF SECTION II OF THE SCHEDULE

	Item	Source
1.	Do you day-dream?	Bell, S.R.A.
2.	Do you frown often?	Woodruff
3.	Have you any habit you think is unusual?	Bell
4.	Are you happy most of the time?	Woodruff
5.	Do you bite your nails often?	S.R.A.
6.	Do you cry easily?	Woodruff
7.	Do you laugh easily?	Woodruff
8.	Do you get very anxious?	Woodruff
9.	Do you get angry easily?	Woodruff

TABLE 3

ITEM SELECTION FOR PHYSICAL SUB-SCALE

OF SECTION II OF THE SCHEDULE

	Item	Source
1.	Do you blink often?	Woodruff
2.	Do you sleep well at night?	Bell, S.R.A.
3.	Do you feel well and strong most of the time?	Woodruff
4.	Do you ever have colds?	Bell, S.R.A.
5.	Do you get many headaches?	Bell, S.R.A.
6.	Do you feel self-conscious because of your appearance?	Bell

APPENDIX D

ITEM SELECTION FOR SECTION III OF THE SCHEDULE

The items for this Section on attitudes and a social work service, and the source of each item, are shown in Table 1.

TABLE 1

ITEM SELECTION FOR SECTION III

	Item	Source
1.	What do you think are the main problems of albinos?	Adorno *et al.*
2.	Do you think albinos should have certain types of jobs?	Adorno *et al.*
3.	Do you think albinos have difficulty in getting jobs?	Adorno *et al.*
4.	Would you work in the same room as an albino?	Triandis
5.	Why do you think people have albino children?	Community beliefs
6.	How clever do you think albinos are?	Adorno *et al.*
7.	Can albinos live like everybody else?	Adorno *et al.*
8.	Do you think they have specific personal characteristics?	General discussion
9.	Do you think albinos should marry?	Adorno *et al.*
10.	Do you think blacks should marry albinos?	Triandis
11.	Would you let your child marry an albino?	Adorno *et al.*
12.	Is there any custom in your tribe that says anything about marriage (or contact) with albinos?	Community beliefs
13.	What colour do you think the children of albinos will be?	General discussion
14.	How do you feel about having albino friends?	Adorno *et al.*, Triandis
15.	Would you eat from the same pot as an albino?	Triandis
16.	Would you sit next to an albino on the bus?	General discussion

TABLE 1 (continued)

	Item	Source
17.	What kind of skin problems do you think they have?	General discussion
18.	What do you think happens to albinos at the end of their lives?	Community beliefs
19.	Is there anything else you would like to add on the subject of albinism?	General discussion
20.	Have you ever had contact with or assistance from social workers?	General discussion
21.	Do you think a social worker could help you with your problems?	General discussion
22.	Why do you think I have asked you all these questions?	General discussion

APPENDIX E

SCHEDULE FOR PILOT STUDY ON ALBINISM IN SOWETO

SCHEDULE FOR PILOT STUDY ON ALBINISM IN SOWETO

Confidential

Date:

Researcher: Mrs. J. Kromberg
School of Social Work, University of the Witwatersrand
and The South African Institute for Medical Research.

General Introduction:

This is a survey being done by a social worker at the University of the Witwatersrand and the S.A.I.M.R. She is doing research on the problems of African young people and would be glad of your help. If you will answer honestly and thoughtfully you will be able to understand yourself better and she will learn to understand you too.

There are no right or wrong answers to these questions, just tell me what you think in each case.

If you have not been living with your parents, answer certain of the questions with regard to the people with whom you have been living.

Identifying Information:

Name:

Address:

Age: Date of Birth: Sex:

Std. at school: Name of school:

Language: Tribe:

Interviewer:

Time taken:

Questions on Adjustment:[1]

1. Can you read? Yes/No
2. Can you write? Yes/No

---

1. Items 1 to 5 were included merely to assist the interviewer in establishing rapport with the respondent.

3.	Do you read newspapers? Which?	Yes/No
4.	Do you read comics? Which?	Yes/No
5.	Do you read books? Which?	Yes/No
6.	Are you satisfied with what you do during the day? Why?	Yes/No
7.	Do you daydream often, sometimes, or never?	
8.	Do you frown often, sometimes, or never?	
9.	Do you blink often, sometimes, or never?	
10.	Have you any habit you think is unusual? If yes, what?	Yes/No
11.	Are you happy most of the time?	Yes/No
12.	Do you feel self-conscious because of your appearance?	Yes/No
13.	Do you like to be the centre of everyone's attention?	Yes/No
14.	Do you find it difficult to speak in class?	Yes/No
15.	Do you sleep well at night?	Yes/No
16.	Do you bite your nails often, sometimes, or never?	
17.	Do you often, seldom, or never feel like running away from home? Why?	
18.	Do you feel happy with your brothers and sisters?	Yes/No
19.	Do you cry easily? When did you last cry and why?	Yes/No
20.	Do you feel well and strong most of the time?	Yes/No
21.	Do you feel you don't belong in your family? Why?	Yes/No
22.	Do you laugh easily?	Yes/No
23.	Do you make friends easily?	Yes/No
24.	Do you get very anxious often, sometimes, never? What sort of things make you anxious?	
25.	Do you think others treat you unfairly? Why?	Yes/No
26.	Do you ever have colds?	Yes/No
27.	Have your relations with your father usually been pleasant? Why?	Yes/No
28.	Do you get many headaches?	Yes/No
29.	Do you get on well with your relatives?	Yes/No
30.	Do you blame others for your troubles?	Yes/No
31.	Do you get angry easily, often, sometimes, never? What makes you angry?	

32. Have your relations with your mother usually been pleasant? Yes/No
    Why?
33. Do you avoid other people? Yes/No
    Why?
34. What are your three main problems?
35. Do you feel you have any special handicaps other people don't have? Yes/No
    What are they?

Now, the social worker doing this research is especially concerned with the problems of albinos in Soweto. So she would like to ask you a few more questions on this subject.

Questions on Albinism:

36. What do you think are the three main problems of albinos?
37. Do you think albinos are more suited to certain types of jobs?
38. What do you think causes an albino to be born?
39. Should albinos live normally like other people? Yes/No
    Why?
40. Do you think they are above average/average/below average in intelligence?
41. Should albinos marry? Yes/No
    If Yes: should they marry blacks
    should blacks marry albinos
    If No: why should they not marry
42. What sort of children can albinos expect to have?
43. How do you feel about having albino friends?
44. Have you ever had contact with social workers?
45. Do you think they could help with your problems?
46. Is there anything else you would like to add on the question of albinism?

Interviewer's Comments:

APPENDIX F

SOTHO TRANSLATION OF THE SCHEDULE[1]

BOSOFE KA SOWETO

KE TABA YA BOTHSEPUWA

LETSATSI:

Mobatlisisi: Mofumahadi J. Kromberg
Sekolo sa Mosebetsi wa Kgahisano,
University of the Witwatersrand.

Lenaneo [illegible]lebana le Bosofe
hammoho le sehlopha sa Taolo

SELELEKELA SA KAKARETSO:

Ke mosebetsi wa Mosebetsi wa Kgahisano ya tswang Yunivesity ya Witwatersrand le S.A. Institute ya Patlisiso ya Meriana. Ke etsa Patlisiso e itseng malebana le botho ba batho ba batjha ba Batala, mme nka thabela thuso ya hao. Nka rata ho o tseba le ho tseba hore o nahana jwang, mme maikutlo a hao ke afe mme ho, kamorero oo ke na le dipotso tse itseng ho o botsa. Haeba o tla araba ka botshepehi la ka monahano o bohlale - o tla ba le hona ho ikutlwisisa ho feta mme le nna tla ithuta ho o utlwisisa ho feta.

Ha ho dikarabo tse nepahetseng le tse sa nepahalang dipotsong tsena - wena o mpolelle seo o se nahanang ho e nngwe le e nngwe.

Haeba o ntse o sa dule le batswadi ba hao araba dipotso tse ding tse itseng malebana le batho bao o ntseng o dula le bona.

Tsebiso e Kgethollang:

1. Lebitso:
2. Aterese:
3. Lesofe/Taolo (Ntsha e le nngwe):
4. Letsatsi La tswalo: Bong:
5. Mosebetsi:
6. Moputso:

---

1. This translation was made by Mr. A.M. Moephuli, of the Department of African languages, University of the Witwatersrand, of a preliminary draft of the schedule. No further translations were required by the interviewers.

7. Thuto: Letho
Dilemo ha o qala sekolo
Dilemo ha o lesa sekolo
Sehlopha seo o se pasitseng
Dihlopha tseo o di feitseng

8. Bodumedi (O wa kereke efe):

9. Histori ya Mosebetsi:

Palo ya mesebetsi eo o e sebeditseng
Nako eo o e dutseng mosebetsing wa hao wa ho qetela
Ho se sebetse - o dutse nako e kaakang.

10. Ho tshwarwa:

Moo o fumanweng molato:
Moo o fumanweng molato empa
wa behwa Katlasa molaó o le Kantle:

Diqoso:

11. Palo ya ho tjhentjha moo o dulang:

12. History ya Ho Kula:

Diopereishene
Ho robeha
Dikotsi (accidents)
Maqeba a hloho
Hlokomelo Ke Psychiatrist
Ho robala sepetlele

13. Na o tsejwa ke ba Mafapha a Kgahisano (social):

Bafe:

14. Bongwana: Ke wena ngwana feela lapeng:
O wa bokae: 1,2,3,4,5,6,
wa ho qetela
Na ho bile le Karohano ya batswadi ba hao
O tseba motswadi a le mong na
Na o hlokofaletswe ke motswadi e mong
Na o ne o se na mme pele o ba dilemo tse-12
Na o ne o se na ntate pele o ba dilemo tse-12
Na o hodisitswe ke leloko (relatives)

15. Dikgahleho:/ O rating:

Diparadi
Radio
Ho bala
Baesekopo
Mesebetsinyana-matsoho (Bo-Makheniki, Ho roka j.j.)
Tse ding: Hlalosa:

Dipotso malebana le Phedisano-mmoho

A: Phedisano-mmoho ya lelapa

16. Na o utlwana hantle le bana beno le dikgaitsedi? (E/Tjhe)

17. Na Kamano ya hao le ntatao ka tlwaelo e ntle na? (E/Tjhe)

18. Na ka nako e nngwe o ye o utlwe eka batswadi ba hao ba nyema moko kabaka la hao? (E/Tjhe)

19. Na ho bile le lerato la nnete le maikutlo a tebileng lapeng la heno? (E/Tjhe)

20. Na kamehla o na le dijo tse lekaneng hammoho le diaparo tse lekaneng lapeng la heno? (E/Tjhe)

21. O ye o ikutlwe eka o ka baleha hae/o se o kile wa ikutlwa eka o ka baleha hae? (E/Tjhe)

22. Na o atisa ho qabana le bana benc, banana le bashemane? (E/Tjhe)

23. Na o ikutlwa hore batswadi ba hao ba o tshwara hantle ho feta tekanyo? (E/Tjhe)

24. Nakamano ya hao le mmao ka tlwaelo e ntle? (E/Tjhe)

25. Na hona le e mong wa batswadi ba hao ya ileng a o etsa hore o se thabe ka ho fumana phoso tseleng eo o shebehang ka yona? (E/Tjhe)

26. Na batswadi ba hao ba ne ba atisa ho o shapa ha o ne o le dilemong tse mahareng a - 10 le 15? (E/Tjhe)

27. Na batswadi ba hao ba rata metswalle eo o tsamayang le yona? (E/Tjhe)

28. Na o ye o atisa ho nahana hore batswadi ba hao ha ba o utlwisise? (E/Tjhe)

29. Na o ye o bone eka metswalle ya hao e na le bophelo ba hae bo thabisang ho feta ba hao? (E/Tjhe)

B. Kamano malebana le mmele:

30. Na o ikutlwa o phela hantle mme o le matla boholo ba nako? (E/Tjhe)

31. Na o ye o swenyc sefahleho

o panye-panye
o lome dinala tsa hao (E/Tjhe)

32. Na o na le mokgwa o mong oo o nahanang hore ha o a tlwaeleha: (E/Tjhe)

Ha o re e : Hlalosa:

33. Na o robala hantle bosiu (E/Tjhe)

34. Na o kgathatswa ke mahlo a kgathalang
ke ho ethimola ho sa feleng
ke ho opa ha hloho
ke maidiidi
ke mokgohlane
ke mahloko a letlalo
ke ho kgathala hara motsheare (E/Tjhe)

C. Kamano ya Kgahisano:

35. Na o rata hore o be ntjhebeng - e mong le e mong a ele wena hloko na? (E/Tjhe)

36. Na o leka ho phema kamano le batho b bang? (E/Tjhe)

37. Na o fumana kapa o ne o fumana ho le thata ho bua ka tlelaseng na? (E/Tjhe)

38. Na o rata ho ba le batho ba bang meketeng-ya-kgahisano (social gatherings) (E/Tjhe)

39. Na o atisa ho buisana le batsamai ba bang beseng kapa tereneng? (E/Tjhe)

40. Na o na le bothata ho qala moqoqo le motho eo o tswa mo tsebiswa haufinyane? (E/Tjhe)

41.a Na o fumana ho le bonolo ho etsa setswalle le batho ba batshehadi? (E/Tjhe)

b Na o fumana ho le bonolo ho etsa setswalle le batho ba batona? (E/Tjhe)

42. Na o emela morao meketeng-ya-kgahisano (Social occasions)? (E/Tjhe)

43. Na o kgona ho etsa setswalle ha bonolo? (E/Tjhe)

D. Kamano malebana le maikutlo:

44. Na o atisa ho thuisa hara motsheare? (E/Tjhe)

45. Na o motho ya lliswang ha bonolo? (E/Tjhe)

46. Na ka nako e nngwe o ye o honohele thabo eo ba bang ekang ba na le yona? (E/Tjhe)

47. Na o kgathatswa ke maikutlo a hore o a telleha? (E/Tjhe)

48. Na o dula o thabile boholo ba nako? (E/Tjhe)

49. Na o halefa haholo ha o pheha kgang le batho ba bang? (E/Tjhe)

50. Na dintho di ye di o tsamaele hampe empa e se ka baka la phoso e entsweng ke wena? (E/Tjhe)

51. Na o Kgotsofetse ka seo o se etsang motsheare? (E/Tjhe)

52. Na o ye o ikutlwe o na le ho-se-itebale (self-conscious) ka baka la sebopeho sa botho ba hao? (E/Tjhe)

53. Na o a Kgathatseha ka bomadimabe bo ka tshwanang bo hlaha? (E/Tjhe)

54. Na o ikutlwa o le bodutu leha o na le batho ba bang? (E/Tjhe)

55. Na o atisa ho ikutlwa o kgathatsehile feela, o sa thaba? (E/Tjhe)

56. Na o atisa ho-tsheha? (E/Tjhe)

E. Dipotso malebana le bosofe:

57. Diqaka (problems) tsa hao tse kgolo, tse tharo, ke dife? 1.
2.
3.

58. O nahana hore diqaka (problems) tse kgolo, tse tharo tsa bosofe ke dife?
1 2. 3.

59. Na o ka rata ho kopana le masofe mme o be le kgahisano le ona?) (E/Tjhe)

60. Na masofe eka kgona a nyalane le batho ba batsho (ke hore bao e seng masofe? (E/Tjhe)

Na batho ba batsho eka kgona ba nyalane le masofe? (E/Tjhe)

Masofe eka kgona a se nyale/nyalwe le letho? (E/Tjhe)

61. Masofe a 'umana bana ba batsho kapa bana ba masofe?

62. Ke eng e bakang hore lesofe le tswalwe?

63. Na o tseba basebetsi ba Mosebetsi-wa-kgahisano (Social work)? (E/Tjhe)

64. Na o se o kile wa fumana thuso ho mosebetsi wa Mosebetsi-wa-kgahisano (social worker)? (E/Tjhe)

Ha o re e; o fumane thuso ho mokgahlo ofe?

Hobaneng:

65. O nahana hore mosebetsi wa Mosebetsi-wa-kgahisano (Social worker) a ka o thusa jwang?

APPENDIX G

INSTRUCTIONS FOR RATERS

Interviews have been held with 70 subjects and schedules completed for each one.

Certain answers to certain items required elaboration. These responses are to be independently rated by two clinical psychologists.

The following instructions are to be followed regarding the rating.

1. You are required to rate the responses for adjustment/maladjustment. The elaboration to the answer is regarded as an indicator of the subject's capacity to adapt to everyday living.
2. For the purpose of rating the following definition of adjustment is to be used:

   'adjustment is a condition of harmonious relation to the environment wherein one is able to obtain satisfaction for most of one's needs and to meet fairly well the demands physical and social, put upon one' (English and English, 1970).
3. The responses to be rated are Nos. 16, 21, 26, 33, 35, 39, 40, 41, 43, 45, 46, 47.
4. Item 48 is open-ended and the response should be rated in the same manner as the responses numbered above.
5. Each response should be rated on a 7-point scale as follows:

-3	-2	-1	0	+1	+2	+3

   Where -3 indicates very severe maladjustment and +3 very good adjustment.

   Eg.: Do you think others treat you unfairly?

   Yes, everyone says unkind things behind my back and at the same time pretends to be my friend.

   Rating: -3
6. If there is no response an X should be inserted in the last column, under the heading 'No Score.'
7. You are supplied with rating sheets for each individual for completion.

   Please insert the number of each schedule, your initials and the date on the respective rating sheet at the top right hand corner. Then proceed through each schedule rating the responses following the 'Why' for the items numbered on the sheet, according to the definition of adjustment as given in No. 2 above. On completion of the rating if there are any comments please write them in the space provided at the bottom of the sheet.

Kindly return the completed sheets to the writer personally.

APPENDIX II

ALBINISM IN SOWETO : SCHEDULE IN RESPECT OF ALBINO AND CONTROL GROUP

Confidential

Date:

Researcher: Mrs. J. Kromberg
School of Social Work, University of the Witwatersrand
and The South African Institute for Medical Research.

General Introduction:

This is a survey being done by a social worker at the University of the Witwatersrand and the Human Sero-Genetics Unit of The South African Institute for Medical Resear .. She is doing some research on the problems of African young people and would be glad of your help. If you will answer honestly and thoughtfully you will be able to understand yourself better and she will learn to understand you too.

There are no right or wrong answers to these questions, just tell me what you think in each case.

If you have not been living with your parents answer certain of the questions with regard to the people with whom you have been living.

I Identifying Information

1. Name:
2. Address:
3. Albino/Control (Delete one)
4. Date of birth: Sex:
5. Occupation:
6. Income:
7. Education: None
   Age on school entry
   Age left school
   Standard passed
   Classes repeated
8. Religion:
9. Occupational History: Number of jobs
   Length of last employment
   Unemployed - how long
10. Arrests:
    Convictions
    Probations
    Offence

11. Number of changes of residence: None
1-2
3-4
5-6
More

12. Medical History:
Operations
Fractures
Accidents
Head injuries
Psychiatric treatment
Skin treatment
Eye treatment
Hospitalization

13. Known to social work agencies:
Which:

14. Childhood: Only child
Position: 1,2,3,4,5,6,last
Separated parents
One Step-parent
Death of one parent
Without mother before 12 years
Without father before 12 years
Raised with relatives
Illegitimate
Other:

15. Interests:
Sport: Participating
Watching: Alone
With friends
Neither
Radio: Alone
With friends
Reading:
Films: Alone
With friends
Hobbies:
Other: (Eg. Church)

II Questions on Adjustment

16. Are you satisfied with what you do during the day?
Yes/No Why?

17. Do you day-dream often?
Yes/No

18. Have you any habit you think is unusual?
Yes/No If Yes: What habit.

19. Are you happy most of the time?
Yes/No

20. Do you often have sweating palms?
Yes/No

21. Are you ashamed because of your physical appearance?
Yes/No Why?

22. Do you often blink?
Yes/No

23. Do you find it difficult to speak in a group of people?
Yes/No

24. Do you sleep well at night?
Yes/No

25. Do you often bite your nails?
Yes/No

26. Do you often feel like running away from home?
Yes/No Why?

27. Do you feel happy with your brothers?
Yes/No

28. Do you cry often?
Yes/No Why?

29. Do you cry when your heart is sore?
Yes/No

30. Do you (your body) feel well and strong most of the time?
Yes/No

31. Are you unhappy with your sisters?
Yes/No

32. Do you feel wanted and needed by your family? (belongingness)
Yes/No Why?

33. Do you make plenty of friends?
Yes/No

34. Do you often get anxious?
Yes/No Why?

35. Do you think others treat you unfairly?
Yes/No Why?

36. Do you often get sick so that you have to stay away from school/ work? Yes/No

37. Is there one sickness that troubles you most?
Yes/No Which?

38. Have your relations with your father usually been pleasant?
Yes/No Why?

39. Do you often get headaches?
Yes/No How often?

40. Do your relatives dislike you?
Yes/No Why?

41 Are other people to blame for any of your present troubles?
Yes/No Why?

42. Have you always been on good terms with your mother?
Yes/No Why?

43. Do you often get angry when you are talking with people?
Yes/No Why?

44. Do you usually speak to strangers on the bus or train?
Yes/No

45. Do you feel you have any special handicaps that other people don't have? Yes/No What are they?

46. Do you feel other people are always looking at you?
Yes/No Why?

47. Do you feel your friends have a happier home life than you?
Yes/No Why?

48. What troubles you most often?

Now, the social worker doing this research is especially concerned with the problems of albinos in Soweto. So she would like to ask you a few more questions on this subject.

III Questions on Albinism

49. What do you think are the main problems of albinos?

50. Do you think albinos should have certain types of jobs?
Yes/No What jobs? Why?

51. Do you think albinos have difficulty in getting jobs?
Yes/No

52. Would you work in the same room as an albino?
Yes/No

53. Why do you think people have albino children?

54. How clever do you think albinos are?
(Above/Average/Below)

55. Can albinos live like everybody else?
Yes/No Why?

56. Do you think they have specific personal characteristics?
Yes/No Why?

57. Do you think albinos should marry?
Yes/No

If yes: should they marry blacks?
should they marry albinos?
If no: why not?

58. Do you think blacks should marry albinos?
Yes/No Why?

59. Would you let your child marry an albino?
Yes/No Why?

60. Is there any custom in your tribe that says anything about marriage (or contact) with albinos?

61. What colour do you think the children of albinos will be?

62. How do you feel about having albino friends?

63. Would you eat from the same pot as an albino?
Yes/No Why?

64. Would you sit next to an albino on the bus?
Yes/No Why?

65. What kind of skin problems do you think they have?
(Does it affect you in any way)

66. What do you think happens to albinos at the end of their lives?

67. Is there anything else you would like to add on the subject of albinism?

68. Have you ever had contact with or assistance from social workers?
Yes/No Why?

69. Do you think a social worker could help you with your problems?
Yes/No How?

70. Why do you think I have asked you all these questions?

Interviewer's Comments: (Eg. Interview went smoothly, subject talked easily/with difficulty. Etc.).

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Name of thesis Albino Youth in Soweto: Some features of their adjusment 1977

PUBLISHER:
University of the Witwatersrand, Johannesburg
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