

ALBINISM IN MALAWI

A QUALITATIVE STUDY ON ATTITUDES AND BELIEFS

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Abstract

Albinism is an inherited, genetic condition. People with albinism exhibit little or no pigment in eyes, skin or hair, and often have problems with vision and sensitive skin.

Albinism in Malawi is a qualitative project that has set out to examine attitudes and beliefs related to people living with albinism in Malawi. The aim has been to assess what implications albinism has on the lives of those born with it, and for their closest network of family and friends.

Individual, in-depth interviews were carried out with 25 people with albinism, their family members and others who were otherwise involved in their lives. Two different translators were used in most of the interviews, as most people in Malawi do not speak English, and the researcher does not speak any of the local languages. The translators were both women with albinism.

The findings show that most people with albinism, as well as their families, have very little knowledge about albinism, but know, and experience that albino-skin is very sensitive to the sun, and therefore take precautions to prevent injury. Stories of common myths were told, as well as stories of different relationships that are altered as a result of one person being albino. Stories were also told of love and approval of people with albinism. In Malawi people with albinism are considered, and consider themselves to be disabled.

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List of Abbreviations

AWA – Albinism World Alliance

DPO – Disabled People’s Organisation

FEDOMA – Federation of Disability Organisations of Malawi

FFO – Norwegian Federation of Organisations of Disabled People

NAD – Norwegian Association of the Disabled

SINTEF – Scientific and Industrial Research at the Norwegian Institute of Technology

TAAM – The Albino Association of Malawi

UDF – United Democratic Front

UN – United Nations

Definitions

Disability: Functional limitations that may occur in any population and in any country in the world. Disability may be permanent or transitory, and can be physical, intellectual or sensory impairment, medical conditions or mental illness (UN 1994).

Handicap: Limitations or loss of opportunities which prevent a person from part-taking in life on an equal level with other members of the community. Handicap is the encounter between a person with a disability and his/ her environment (UN 1994).

Albinism: Albinism is a genetic, inherited condition. A person with albinism (an albino) has little or no pigment in eyes, skin and hair, often with sensitive skin and low vision. The intelligence of people with albinism falls within the normal range (Gaigher et. al. 2002, p. 4).

1.1 Introduction

This thesis is based on a qualitative study about albinism in Malawi. Not many studies have been done on the topic of albinism in Africa or elsewhere, there is no current scientific literature available about albinism in Malawi, and to my knowledge, no previous research in the field of albinism in Malawi has been carried out. People with albinism in African countries, one could expect, have a very different life situation than people with albinism from countries where the majority of the population is Caucasian. Studies on the topic of albinism in other African countries also suggest this. In western/Caucasian countries people with albinism do not stand out as much as they do in countries where the majority of the population is black. In many African countries albinism is considered a disability, and people with albinism often consider themselves to be disabled. In western countries, however, there is – to this day- a controversy as to whether or not albinism is a disability (NOAH- 3).

Studies and literature on the topic of disability and albinism often make the assumption that people with disabilities have a poor quality of life, and are exposed to a great deal of stigmatization and discrimination. For the purpose of this study, however, it has been important not to make any assumptions or conclusions beforehand, to keep an open mind. The aim has been to look at people's quality of life, to see if they are exposed to any type of stigma or discrimination.

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1.2 Background



1.2.1 Malawi

The **Republic of Malawi** is located in the Southern Central Africa, and has a population of approximately 11 million people. It is a very poor country; one of the 12 poorest in the world by UN estimates (UNAIDS 2002). English and Chichewa are official languages (World Factbook), but the literacy rate is only 58% (72, 8% for men, and 43, 4% for women) (UNAIDS 2002).

Malawi's economy is predominantly agricultural, and approximately 90% of the population live in rural areas (Loeb and Eide 2004, p. 29).

Malawi was a British protectorate, then under the name of Nyasaland, from 1891 to 1953. In 1953 Nyasaland joined a federation with Rhodesia (now Zimbabwe and Zambia), and this federation was dissolved in 1963. In 1964 Malawi became an independent country, with Hastings Banda as president. Banda's presidency soon developed Malawi into a dictatorship (NORAD 2003). After three decades of this repressive one-party rule, Malawi became a democracy in 1994, with the election of President Bakili Muluzi (from the United Democratic Front; UDF), who presided for ten years. New elections were held in June 2004, with the election of the current president; President Bingu Wa Mutharika (also from UDF).

1.2.2 Disability on the International Agenda

In the past few decades efforts have been made on the international agenda to improve the situation for people with disabilities. With the International Year of Disabled Persons in 1981, The World Programme of Action concerning Disabled Persons in 1982, and the development of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN 1994), awareness was raised on the topic, and programs put into action (UN 1994). The Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN 1994) were adopted by the United Nations General Assembly on 29th of December 1993. The main purpose of the rules is to make sure that people with disabilities have the same rights as other members of a society. The rules are not compulsory, but they are enforcements with a strong moral and political commitment.

In Malawi disability is on the agenda, and the Standard Rules were implemented with the initiation of a multi-party democracy in 1994. A report written in 1997 (Michailakis 1997) does show, however, that as of 1997 there was no officially recognized disability policy in Malawi, and although the government had at that stage adopted the standard rules on the equalization for people with disabilities, nothing had been done to convey the message of full participation for people with disabilities. No benefits are guaranteed by law to persons with disabilities. There is a national umbrella organization for people with disabilities; Federation of Disability Organisations in Malawi (FEDOMA), but disabled people's organizations (DPO's) are not consulted when laws and regulations with a disability aspect are being prepared. Organizations for persons with disabilities are not given any government support (Michailakis 1997). The Ministry of Social Development and People with Disabilities in Malawi was established around the turn of the century. The ministry is currently working on a national disability policy which is expected to be finalized this year. Norwegian Association of the Disabled (NAD) is supporting both the

development of the ministry, and the National Disability Policy (Brodtkorb & Kisubi 2001).

A survey on living conditions among people with disabilities has been conducted in Malawi. The survey was collaboration between FEDOMA, Norwegian Federation of Organisations of Disabled People (FFO) and SINTEF Health Research in Norway. The survey, finalized in 2004, showed that there are systematic differences between people with and people without disabilities. People with disabilities are in many cases worse off than those without disabilities; in economic situations, schooling and job opportunities (Loeb and Eide 2004, pp. 17). It was, however, noted that people with disabilities were not much affected by their disability status in family settings (Loeb and Eide 2004, pp. 157-159).

1.2.3 Albinism

Albinism is a genetic, inherited condition. A person with albinism (an albino) has little or no pigment in eyes, skin and hair, often with sensitive skin and low vision. The intelligence of people with albinism falls within the normal range (Gaigher et. al. 2002, p. 4). It has been estimated that in the USA one person in 17,000 has some type of albinism. Studies from Africa, however, show that the prevalence of albinism in Africa is approximately one in 4000 (Lund 2001 & Lund and Gaigher 2002). A common myth about albinism is that all people with albinism have red eyes, but this is very often not the case. Most people with albinism have very light skin and hair, but not all. This depends on the type of albinism, and some types are only classified as albinism due to eye problems. In my study I have focused on people with albinism who have light skin and hair. Many of these people have skin-problems, and in tropical countries it is not uncommon for them to develop life-threatening skin-cancers if they do not use skin

protection (sunscreen lotions rated 20 or higher) (NOAH – 1). Black Americans with albinism have said that they experience difficulties in terms of social problems related to cultural or racial taboos, myths and misunderstandings connected to their looks. One very common myth has been described which claims that a non-Caucasian person with albinism must be the result of mixed marriage. These types of myths can cause a tremendous amount of stress on the family and on the child with albinism (NOAH – 2).

African history contains stories and myths describing albinism. Attitudes, tales and myths have developed and changed over centuries. One story suggests that albinism is the product of a Negress-gorilla or Negress-water spirit mating. In some places in South Africa today people with albinism are still referred to as 'nkau', which means monkey. Other myths about albinism refer to blessings as well as punishments, and skills in sorcery as well as healing, and so on (Kromberg et. al. 1987, p. 911).

One myth I came across during this study has also been described in a study by Lund and Gaigher (2002). This is the myth that albinism is the result of witchcraft. Myths of this kind suggest that families with babies that have albinism are victims of witchcraft which has led to the baby being born with albinism (Lund and Gaigher 2002, p. 370).

Lack of knowledge about albinism can lead to many superstitions, and this, combined with poverty, also magnifies problems related to skin and eyesight (Lund 2001).

There has not been done many studies on the topic of albinism, and there is – to this day – a controversy as to whether or not albinism is a disability (NOAH- 3). The American National Organization for Albinism and Hypopigmentation (NOAH) is one of the few organizations for people with albinism in the world today. The organization is primarily run and funded by its members, and the aim of the organization is to provide information,

awareness and support about albinism and related conditions (NOAH- 4) NOAH is part of the Albinism World Alliance (AWA), as with several other albinism organizations across the world (NOAH- 5). As mentioned earlier, Malawi has an organisation for people with albinism; The Albino Association of Malawi (TAAM). This organisation is also registered as a member of the Albinism World Alliance (AWA), as well as a registered member of FEDOMA. TAAM is an organisation which receives very little funding, and has limited means to ensure its success. Since its start in 1995 it has not been able to do much for its members.

1.2.4 Stigma

‘A stigma is a special kind of relationship between attribute and stereotype’

(quote Goffman 1997, p. 204)

Stigma, or rather the possibility of stigma, is a central concept in this project. For the purpose of this project when I am referring to stigma, I will be referring to Goffman’s notion of stigma, as brought forward in the book ‘Stigma: Notes on the management of spoiled identity’ (1963). Goffman has been, and continues to be very influential on the topic of stigma in the social sciences. His ideas and concepts have been used and disputed in many studies. Goffman (1997) defines a stigmatised person as someone who possesses undesirable characteristics that are not within the normal characteristics in the category he belongs to. This person is thus reduced in our minds from a whole and normal person to a tainted, discounted one. Goffman argues that society establishes categorizations, where certain characteristics are considered normal within a category, the outcome can be referred to as social identity. According to Goffman social identity is based on first appearances, and occurs through mixed contacts, that is social situations where stigmatised are in contact with ‘normals’. Our anticipation of others, our assumptions as to what the person is like, is often based on these first appearances (Goffman 1997). He

distinguishes between people who are discredited and people who are discreditable. A discredited person is someone whose differences are evident on the spot, while a person who is discreditable possesses undesirable characteristics that are not immediately perceivable to those present. Goffman describes three types of stigma: First; abominations of the body, like physical deformities, second; blemishes of individual character, and third; tribal stigma, referring to race, nationality and religion. A person who is stigmatised is seen as a victim, inferior, and someone who is not quite human. Goffman describes a dilemma for 'normals' in how they should treat a stigmatised person. The dilemma lies in finding a balance between making impossible demands where the stigmatised has a shortcoming, and on the other hand giving these individuals full participation. These situations can make some sort of 'secondary gain' for stigmatised people, in that they can escape from the responsibilities of 'normals', hiding behind their stigma (Goffman 1997).

Goffman talks about normality as a counterpart to stigma, but he does not explain what normality is, or how it is constructed. Davis (1997) makes an attempt at doing this, and also at explaining why the notion of normality is so important for the understanding of disability. Davis (1997) argues that we live in a world of norms, of average people, where we aim to be normal, or deliberately try to avoid being normal, but it revolves around normality. People compare themselves to others. To understand disability, one must return to the concept of normality, and the normal body. Davis states that:

'...the problem is not the person with disabilities, the problem is the way that normalcy is constructed to create the 'problem' of the disabled person' (quote Davis 1997, p. 9).

One of the main criticisms to Goffman's notion of stigma is his argument that stigma is a fixed concept. Coleman (1997) argues that stigmas mirror culture and society, and that they are in constant flux. He states that:

'Stigma represents a view of life; a set of personal and social constructs; a set of relations and relationships; a form of social reality' (Quote p. 216).

While Goffman (1997) argues that certain characteristics are undesirable and abnormal, and others are normal, Coleman (1997) says that these notions are culture bound. What is normal and desirable differs in different cultures and within cultures as well. Coleman argues that it is the dominant group in a given setting that sets the standards for which human differences are desirable and undesirable. But while stigma differs in different societies, Coleman says that three important aspects are always present where stigma is present. The first aspect is fear, which is stigma's primary affective component; people are afraid of the unknown, and acts accordingly. The second aspect is stereotyping, which is stigma's primary cognitive component; a way of rationalising the unknown. The third aspect is social control, which is stigma's primary behavioural component; our actions towards stigmatised individuals (Coleman 1997).

Like Coleman (1997), Album (1995) also argues that Goffman sees social relations as static and ritual, and not changing depending on the social setting one is in. Album writes of Goffman's earlier works, before his work on stigma. In this work Goffman wrote about how people interpret one another, which methods people use to draw conclusion as to what other people are like. Goffman argues that there are strict rules for behaviour and rituals, and that people act within these rules, or 'frames'. Album, on the other hand, argues that behaviour and attitudes change from one social setting and situation to another, and that people behave differently depending on the setting. This can be drawn in comparison with Goffman's notion of stigma, as stigma is a social construction, but

Goffman says that stigma is static, and controlled by strict rules and regulations (Album 1995).

Parker and Aggelton's (2003) argument build on Album's (1995) argument. They argue that Goffman's notion of stigma is difficult to use in a cross-cultural setting, as Goffman describes stigma as a static attitude, rather than a constantly changing social process. Parker and Aggelton (2003) argue that Stigma is constructed through interaction, and must be understood through interaction. Interaction differs in different settings, and so does stigma. Stigma is a social process, which operates in relation to difference and also in relation to social and structural inequalities.

1.2.5 Disability and Stigma

In much of the literature about disability it has been assumed and concluded that people with disabilities are exposed to stigmatisation, discrimination, and sometimes even maltreatment.

Michalco (2002) writes of his own experiences as a blind person. He has written several books about his disability, but in the book 'The Difference that Disability Makes' (2002) much of the focus is on the social construction of disability, and how cultural assumptions and stereotypes put limitations on the lives of people with disabilities. Michalco (2002) tells his own story of suffering, a suffering connected as much to society's construction of his disability, as to the disability itself. Michalco (2002) tells of his meeting with the medical profession when he was losing his sight as a child, and he also tells of his continuous meetings with various aspects of society. Along with the influence of these, he tells of his own dealings with his disability and his constructing an identity as a disabled person. Disability is, according to Michalco, viewed as something that happens to a person for various reasons, often depending on the culture in which it occurs. So disability is something that happens TO a person, not what a person IS.

Michalco (2002) argues that the society where he lives (western society) views disability as a problem of inability, or a lack of ability to function as 'normal' people. He does not specify what is considered normal in this argument, but he links the definition to the biomedical paradigm;

'The biomedical paradigm sees disability as something wrong with the biological body and thus constructs disability as a medical problem.'

(quote Michalco 2002, p. 13)

It has been argued that a sense of self is born in the interplay between the external world and each individual's internal response. Albinism is a very important part of that sense of self (NOAH-3, p. 1). A study (Wan 2003) has been done on this topic, and on individual coping-strategies. This qualitative study, conducted at Douglas Hospital Research Center in Canada, concerns experiences and coping strategies of twelve people with albinism from various (western/white) countries globally. Eight coping strategies of resistance to stigma are identified, and these, Wan (2003) states, are *'essential elements of personal change and even, possibly, social change'* (quote Wan 2003, p. 277). The study is framed around Goffman's theory of stigma. The objective of this study is *'...to provide an overview of the adversities that people with albinism face and the mechanisms they develop to deal with them'* (quote Wan 2003, p. 279). It is assumed that people with albinism experience stigmatization and marginalization all over the world, and the researcher set out to examine this, and how people develop coping strategies. As mentioned earlier, however, the aim of my study has been to examine whether or not these phenomena were present at all, and if so; to what extent and how it affected the lives of people with albinism.

A study from South Africa suggests that it is the social context, as much as the physical condition, that structure and limit the lives of people with albinism. In this study

32 children with albinism, at a special school in the Limpopo province of South Africa, were interviewed. The study is sociological, focusing on educational, health and social problems, as well as attitudes and perceptions about albinism. The data from this study revealed lack of information and knowledge about albinism. It was found that albinism was seen as a condition immersed in myths and superstition, and as a result of this children with albinism experienced a great deal of stigma and rejection (Gaigher et. al. 2002).

Ingstad (1995) disputes what she refers to as a generalization that has been made to draw attention to the situation of disabled people worldwide. A generalization saying that disabled people in developing countries live in '*a state of utter misery and neglect*' (quote Ingstad 1995, p. 246), resulting in what Ingstad refers to as a 'myth of the hidden disabled' (which is the title of Ingstad's book on this subject). Ingstad argues that this is to a large extent a myth created to get political support and funding to programs giving priority to disabled people as a group in society. Ingstad disputes the myth on the basis of her own meetings, observations and conversations with these so-called 'hidden disabled' and their families (Ingstad 1995). Out of 100 disabled persons interviewed, Ingstad was taken to eight different disabled people that were said to be hidden, neglected and abused, and the outcome was that:

'Among the eight cases that were shown to me by the rehabilitation workers as examples of hiding, neglect, or abuse, only two proved to be so to some extent when looked into closely. And even in those two families we found that the situation of the disabled person was mainly a reflection of the general hardships that all household members were living under' (quote Ingstad 1995, p. 252).

Ingstad's point is not that neglect and hiding do not happen, but that we must have empirical evidence for statements of hiding and neglect, and not assume that it occurs universally. Such phenomena must be seen and understood through the different context where it occurs.

Albrecht and Devlieger (1999) also refer to a myth related to people with disabilities.

'Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence?'
(quote p. 977).

This myth talks of the notion that people with disabilities are seen to have a very poor quality of life. The authors talk of a disability paradox, referring to studies of disabled people where they were asked how they perceive their own quality of life. Most replied that they had a very good quality of life, and so the disability paradox was created.

1.2.6 For Future Studies

This study is based solely on qualitative research techniques and results. The results have revealed certain issues and problems related to albinism, but these results can not be said to be representative for the population of people with albinism in Malawi. The study has, however, brought issues to the surface that could be looked at and studied further. A longer, more in-depth study into the topics that has been raised throughout my study could be very interesting and useful to highlight, to get a better understanding of the lives of people with albinism. I, the researcher, am a beginner in the field of research. As much as this project has brought forward some very useful data, I have learnt throughout this study many things that could have been done differently to make the quality of the data

even better. I will be going into more detail about this in the 'Methodology and Sample' section.

This project has had a limited time-limit due to it being part of a two year masters degree at the University of Oslo. This must be taken into consideration when looking at the amount of data collected, as well as its validity. To truly understand a field like this one should spend much more time in the setting.

Further studies about albinism in Africa could contribute to a very limited body of knowledge in the field. It could also help bring more awareness to albinism, on a social level, as well as on a governmental level. As this study, and other studies before it has shown, there is very little knowledge and awareness about the topic albinism in Africa. This leads to not just to social problems, but also to physical problems in terms of skin and eyesight. More awareness is needed to assure that people with albinism are provided with what they need both socially and materialistically to live a fulfilled life.

2.1 Methodology and Sample

2.1.1 Literature Review

The first part of this master thesis was an extensive literature review, covering important literature in the fields of disability, culture and albinism, as well as literature on Malawi, stigma and discrimination. This process was important to get an overview of the field in which fieldwork was to be done and to learn from previous studies. The literature review was finalized in a literature review exam, which then led on to making a project proposal. In the project proposal, objectives were made, and these objectives have been used as a guide throughout the study.

2.1.2 Objectives

Main Objective:

- Examine attitudes and beliefs related to people with albinism, and assess implications of these on the lives of people born with albinism, as well as for their closest network of family and friends.

Specific Objectives:

- Explore attitudes on marriage in regards to people with albinism
- Explore events in the lives of people with albinism, and how people think these events have influenced their lives
- Explore people's knowledge about albinism
- See if there is a difference between people with albinism in urban and rural settings
- See if there is a difference between males and females with albinism
- Look at the affect of poor eye-sight and skin problems; do they get any help?

2.1.3 Study Design

This is a qualitative study, where only qualitative research methods have been used. The choice of a study design depends on what one wishes to accomplish with a study. To impose an unsuitable research design on a study could lead to loss of credibility for the project, in terms of results of poor validity. For this particular project qualitative methods were deemed suitable because it is a study which has aimed to understand and explore an area where the previous knowledge is very limited. This study is a search for in-depth knowledge and people's lived experiences. In this project, and others like it, it is impossible to predict the outcome of the study, and hence it is necessary to use methods that will reveal the research questions from the data (Morse & Richards 2002, pp. 27-28). In quantitative studies hypotheses can be made as to what the outcome of the study will be, and this hypothesis is either supported or denied by the research results. In this study, one can not make such a hypothesis. In this study the aim has been to learn from the subjects about their views and knowledge, to explore their points of view. To do this, Morse & Richards (2002) argue that 'you need methods that will allow you to discover and do justice to their perceptions and the complexity of their interpretations' (quote p. 28), qualitative methods can do this. This study further aim to explore the phenomena of albinism in detail, to create a broader understanding of how it is perceived in a Malawian context, for this Morse & Richards (2002) argues 'you need methods for discovery of central themes and analysis of core concerns' (quote p. 28).

As much as I believe that for the purpose of this project qualitative methods were right, I also believe that for further studies in this area it would have been useful with a study using quantitative methods. This study has now provided us with some pointers as to what could be looked further into, and what is important for people with albinism. This study can not, however generalise as to what the situation is like for people with albinism

in Malawi, it can just tell us what the people that I have spoken to experience. This is where a quantitative project could be very useful, and provide us with further knowledge in this area. As quantitative projects cover a representative sample size of a given population (in this case that would be the population of people with albinism in Malawi), this type of study would be useful to provide an understanding of the situation for the majority of the population of people with albinism in Malawi.

2.1.4 Study Site

As mentioned earlier, this study was carried out in the **Republic of Malawi**, which is located in the Southern Central Africa.

One part of this study was done in Blantyre district, while the other part was done in Mangochi district. Blantyre district is an urban district, while Mangochi district is a large, rural district. The climate is very different in these two districts. Blantyre is a highland district, and therefore much cooler than Mangochi district, which is mainly a low-land district. Mangochi district is to a large extent centered on Lake Malawi, and has a very tropical climate.

2.1.5 Sampling

Before I entered the field I was afraid that it would be difficult to find people that would talk to me, but it turned out to be quite the opposite. Most of my informants in Blantyre district were found through the village headman of the village in which they lived. I was told that it was important to inform the village headmen of my study, and when I did this, they were more than helpful in helping me find informants. The villages I visited were picked by chance, and how many I interviewed depended on how many people with albinism lived in that particular village, and how many were available for interviewing.

In Mangochi district my translator was a nurse, and she was also a lady with albinism. She knew quite a few people with albinism living in the district, and she brought me to them. For a period of time I also helped her distribute sunscreen to people with albinism in Mangochi district¹, and during this time I also came across people I could interview.

2.1.6 Study Population (informants)

The study population for this study was people with albinism, their family members, and other people otherwise involved in the lives of people with albinism. 25 people were interviewed, of them 11 people with albinism, 11 mothers of children with albinism, two siblings of people with albinism, and the leader of The Albino Association of Malawi (who is also a person with albinism). 17 interviews were done in Blantyre district, and six in Mangochi district. More interviews were conducted in Blantyre district because it was easier to find subjects there, and they were easier to access.

All the subjects were either speaking Chichewa or English, and so the people speaking any of the other local languages were excluded from the study. This was done because the two translators that were used could only speak English and Chichewa, and also because the majority of the Malawian population speak Chichewa.

Participation in this study was voluntarily, and this was made clear to the subjects either by a participant information sheet, or orally by the interviewer. Participants were assured to be kept anonymous, and they signed a consent sheet. All the participants were asked if they would have their picture taken, and if it was okay for their picture to be used in this master thesis, or in other writings or presentations related to it. The people whose pictures I have used have all consented to this.

¹ This was done for a Dutch organization. This organization collects sunscreen in Holland, and sends it to Malawi for distribution to people with albinism. For more information about this sunscreen project, see: www.afrikaansealbinos.nl

2.1.7 Data Collection Methods

The data collection methods used in this study was individual in-depth interviews and participant observation.

Qualitative research interviews are like conversations, but as explained in Kvale (1996, p. 6), these interviews are not conversations between equal partners. The conversations are controlled by the researcher, who is the person with a purpose and goal with the interview/ conversation. The researcher introduces the topic for the conversation and guides the conversation (Kvale 1996). One of the biggest challenges with qualitative interviews as research methods is the validity of the knowledge obtained for the social world in which it is found (Kvale 1996). Validity is connected to interpretation. This could be the interpretation of the interviewee of the question asked by the researcher, or it could be the researcher's interpretation of the respondent's answer. To ensure validity the researcher must make sure that questions and statements are clear and easy to understand, and avoid ambiguous words and formulations. On the other hand, to ensure the validity of the subjects responds, the researcher can ask follow-up, -and clarifying questions, or repeat the answer and say 'is that what you are saying?' (Kvale 1996, p. 217-228).

Individual, in-depth interviews were done with all the subjects. An interview guide (Appendix 1) had been made beforehand, and the same guide was followed in all the interviews. The interview guide was made to cover all the topics listed in the objectives of the study. Different guides were made for people with albinism, for parents, for siblings, and for people working on an organizational level in the field of albinism. All the guides covered most of the same topics, but some of the specific issues covered where different. When conducting the interviews it was a good tool to have an interview guide, but the guide that looked good and appropriate while making it in Oslo seemed a bit too broad when applied to the Malawian setting. I felt that I was trying to cover too many

topics, when I should have gone much more in detail in just a few topics. The interviews certainly got better towards the end of the fieldwork, when I, the researcher, was becoming more experienced and confident in the field. But I did follow the same interview guide throughout the study, as I thought it would be appropriate for all the interviews to cover the same topics. In retrospect I would have made a more concise interview guide, with fewer topics, but in much more detail.

The interviewer was the author, but in most of the interviews an interpreter was needed, as few of the subjects spoke English, and the interviewer did not speak the local language, Chichewa. Two different interpreters were used where the subjects did not speak English. This was the case in 17 of the 25 interviews. Both interpreters were local Malawian women, and they were also people with albinism. None of them had any previous experience in interpretation; one was a nurse, and one had data-collection experience, and worked for a disability organization. The two interpreters turned out to be the two most important people for my study. Not only were they locals, and could explain to me the cultural aspects of the setting in which I was doing my field work. They were also women with albinism, and as time went by and we got to know each other, they provided me with information and understanding about what it is like to be a person with albinism in Malawi. But, as mentioned above, neither of my interpreters were skilled interpreters, and this is likely to have created a bias to my study. I tried, to the best of my knowledge, to train my interpreters in the skill of interpreting for me, but this certainly also comes with a bias, as I am not a skilled interpreter either. It must be taken into consideration in this study that some information may have gotten lost in the process of interpretation. The interviews that were done in English, without the help of an interpreter were of much better quality than those where interpreters were used. These interviews were often longer, and the information gained broader and of better understanding to me, the researcher. This was probably because it was easier for me to

ask follow-up questions where things were unclear, and it was also easier for me to steer the interview in the direction I wanted it to go.

Another bias to this study is the experience of the researcher. As this study is part of a master degree, this study is also part of a learning experience for the researcher. As mentioned above, I felt that I, as a researcher, became better at interviewing and getting information the longer I had stayed in the field. In an interview setting I got better and better at asking questions in ways that encouraged the participants to tell and talk.

The researcher spent a lot of time with both interpreters, and I used this time as a type of participant observation. As mentioned before, both my interpreters shared with me many of their thoughts about albinism, and about Malawian culture and society. This was done over a longer period of time, during which I spent time with them in various cultural and social settings. I experienced these two women with albinism both in their normal social settings, and outside of their normal social settings. This gave me a lot of views on how they were treated by people who know them, and are used to them, as well as how they are treated by strangers, and stranger's reactions to them.

2.1.8 Time Frame

The time frame for this project was limited to the time frame for the degree in Master of International Community Health. The degree has a two year/ four semesters limit, with three semesters for thesis development, fieldwork and write up. Spring semester 2004 was devoted to developing the research plan, including literature review, methodology and project proposal. Fieldwork was done in Malawi from June till December 2004, and spring semester 2005 was devoted to data analysis and writing the thesis.

2.1.9 The Researcher as a Tool

The skills, knowledge and background of the researcher contribute greatly to the outcome of a study. I, the researcher in this project have a background in anthropology and psychology, and I have put those skills into use while collecting data for this project. Anthropology is a field of qualitative methods, as is this project. Social factors should also be considered, such as nationality and languages. I am Norwegian, and speak fluent English, but in many parts of Malawi people do not speak English. It has therefore been necessary to use interpreters, and this is likely to have had an impact on the relationships between me and my informants. A white researcher, who is also a woman, is someone who represents differentness in an overall black society, and this may have caused bias to the research results.

I also have experience from working with people with disabilities in Norway. This has provided me with an interest in the field, and also with a greater understanding of the field of disability and 'differentness'.

However, as mentioned above, this was the first fieldwork I have ever done, and so this was my first practical experience in the field. The fieldwork was conducted by me alone. It was an attempt at putting theoretical knowledge into practice, and it was a learning experience every step of the way.

2.1.10 Ethical Considerations

'[Qualitative research techniques] are [...] the most invasive, intrusive, and morally challenging; the only reason a researcher should consider using them is that the research problem requires them' (quote Morse & Richards 2002, p. 29).

Taking into consideration the statement above from Morse and Richards (2002), measures were made in this study to make sure the project was ethical. All participation

in this study was voluntary, and the informants were free to withdraw at any time. No compensation was given to the participants, but the translators received a small fee for their work. The informants were kept anonymous, and their name or picture will not be released to anyone or anywhere without their consent. The information above was given to the informants before an interview, and both they and I signed a consent sheet (Appendix 3). If the informants were illiterate, consent was given orally on a Dictaphone. The oral consent was kept by me, and the information sheet (Appendix 2), signed by me, was given to the informant. Both the participant information sheet and the oral consent sheet were translated into Chichewa, and these forms were given to the informants that did not speak English.

Interviews were taped when the informants agreed to this. At the request of the informants, a summary of the research results can be provided, after the research is finished. When an informant was below the legal age in Malawi (18 years), consent was given by one of his/ her parents or guardians for participation in this study. They were also invited to be present at the interview. Their presence was then noted, and taken into consideration during data analysis.

It was explained to all the informants, both orally and in the written Information Sheet, why I was there, and why I wanted to talk to them. The interpreters were both asked if they could also be used as informants. This was only done towards the end of the study, when I came to realise the importance of their role in my study and in my understanding albinism. It was then explained to them that I wanted to use my experiences with them and of them in my study, and they both agreed to this being done.

Ethical clearance was sought and obtained from ethical committees in both Norway and Malawi.

2.1.11 Data Handling

After the fieldwork all the interviews were transcribed, and all the field notes put together.

All the information was categorized into different topics, as talked about in the attached journal article.

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4.1 Journal Article

*‘Albinism in Malawi: Attitudes and beliefs from an
African Setting’*

by

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Abstract

Albinism is an inherited, genetic condition. People with albinism exhibit little or no pigment in eyes, skin or hair, and often have problems with vision and sensitive skin.

Albinism in Malawi is a qualitative project that has set out to examine attitudes and beliefs related to people living with albinism in Malawi. The aim has been to assess what implications albinism has on the lives of those born with it, and for their closest network of family and friends.

Individual, in-depth interviews were carried out with 25 people with albinism, their family members and others who were otherwise involved in their lives. Two different translators were used in most of the interviews, as most people in Malawi do not speak English, and the researcher does not speak any of the local languages. The translators were both people with albinism.

The findings show that most people with albinism, as well as their families, have very little knowledge about albinism, but know, and experience that albino-skin is very sensitive to the sun, and therefore take precautions to prevent injury. Stories of common myths were told, as well as stories of different relationships that are altered as a result of one person being albino. Stories were also told of love and approval of people with albinism. In Malawi albinos are considered, and consider themselves to be disabled.

Introduction

I found a myth about albinism in a book of oral literature from Malawi (Schoffeleers&Roscoe 1985, pp. 106-108). This is an ancient myth, passed on orally from generation to generation. The myth does not seem to exist in today's Malawian society; none of the people I asked had ever heard of it. It does, however, show that the concept of albinism has existed for a long time in Malawian culture, and always associated with an element of fear and negativity. The myth is called 'The origin of albinos', and it tells the story of two people who are about to be married, but before they are lawfully wed, they have sexual intercourse. As a result they have four children born without a body and limbs, just a head. This was seen as punishment from the Gods for the sin they committed before they were married. The first three children were thrown into the river, and eaten by the crocodiles, but the fourth child the mother insisted on keeping. So she raised this child, which was only a head, and as he grew older, he spoke of his desire to be married. It was not easy for the mother to find a woman to marry her son, but one woman who had been rejected in marriage before agreed to marry 'the head'. After they were married, while asleep, at midnight, the head broke open, and out came an albino. When the wife saw that her husband now had body and limbs, she embraced him, and she too turned into an albino. They had many albino children, and they were happy. But other people kept away from them, and no one came to visit them. The myth says that people with albinism today are still a punishment from the Gods, for the sin that the first pair committed before they were married.

This article is based on a qualitative study about albinism in Malawi.² It will contain stories, such as the myth above, and others like it. Not many studies have been done on the topic of albinism in Africa or elsewhere, and there is – to this day- a controversy as to whether or not albinism is a disability (NOAH- 3). There is no current scientific literature available about albinism in Malawi, and to my knowledge, no previous research in the field of albinism in Malawi has been carried out. People with albinism in African countries, one could expect, have a very different life situation than people with albinism from countries where the majority of the population is Caucasian. The myth mentioned above also suggests this. In western/Caucasian countries people with albinism do not stand out as much as they do in countries where the majority of the population is black.

Studies and literature on the topic of disability and albinism often make the assumption that people with disabilities have a poor quality of life, and are exposed to a great deal of stigmatization and discrimination. For the purpose of this study, however, it has been important not to make any assumptions or conclusions beforehand, to keep an open mind. The aim has been to look at people's quality of life, to see if they are exposed to any type of stigma or discrimination.

² This study was conducted as a partial completion of a master degree in International Community Health. The supervisor for this project was Benedicte Ingstad. I would like to extend my gratitude to Save the Children Norway for their financial contribution to this project, and also to my supervisor for her inspiration and guidance.

Background

Albinism

Albinism is a genetic, inherited condition. A person with albinism (an albino) has little or no pigment in eyes, skin and hair, often with sensitive skin and low vision. It has been estimated that in the USA one person in 17,000 has some type of albinism. Studies from Africa, however, show that the prevalence of albinism in Africa is approximately one in 4000 (Lund 2001 & Lund and Gaigher 2002). People with albinism have very light skin and hair, and they often experience skin-problems. In tropical countries it is not uncommon for them to develop life-threatening skin-cancers if they do not use skin protection (sunscreen lotions rated 20 or higher)(NOAH – 1).

Stigma

‘A stigma is a special kind of relationship between attribute and stereotype’

(quote Goffman 1997, p. 204)

Stigma, or rather the possibility of stigma, is a central concept in this project. For the purpose of this project when I am referring to stigma, I will be referring to Goffman’s notion of stigma, as brought forward in the book ‘Stigma: Notes on the management of spoiled identity’ (1963). Goffman has been, and continues to be very influential on the topic of stigma in the social sciences. His ideas and concepts have been used and disputed in many studies. Goffman (1997) defines a stigmatised person as someone who possesses undesirable characteristics that are not within the normal characteristics in the category he belongs to. This person is thus reduced in our minds from a whole and normal person to a tainted, discounted one. Goffman argues that society establishes categorizations, where certain characteristics are considered normal within a category, the outcome can be

referred to as social identity. According to Goffman social identity is based on first appearances, and occurs through mixed contacts, that is social situations where stigmatised are in contact with 'normals'. Our anticipation of others, our assumptions as to what the person is like, are often based on these first appearances (Goffman 1997). He distinguishes between people who are discredited and people who are discreditable. A discredited person is someone whose differences are evident on the spot, while a person who is discreditable possesses undesirable characteristics that are not immediately perceivable to those present. Goffman describes three types of stigma: First, abominations of the body, like physical deformities. Second, blemishes of individual character, and third, tribal stigma, referring to race, nationality and religion. A person who is stigmatised is seen as a victim, inferior, and someone who is not quite human (Goffman 1997).

One of the main criticisms to Goffman's notion of stigma is his argument that stigma is a fixed concept. Coleman (1997) argues that stigmas mirror culture and society, and that they are in constant flux. Album (1995) also argues that Goffman sees social relations as static and ritual, and not changing depending on the social setting one is in. Parker and Aggelton's (2003) argument builds on that of Album (1995). They argue that Goffman's notion of stigma is difficult to use in a cross-cultural setting, as Goffman describes stigma as a static attitude, rather than a constantly changing social process. Parker and Aggelton (2003) argue that stigma is constructed through interaction, and must be understood through interaction. Interaction differs in different settings, and so does stigma. Stigma is a social process, which operates in relation to difference and also in relation to social and structural inequalities.

Goffman talks about normality as a counterpart to stigma, but he does not explain what normality is, or how it is constructed Davis (1997) makes an attempt at doing this,

and also at explaining why the notion of normality is so important for the understanding of disability. Davis (1997) argues that we live in a world of norms, of average people, where we aim to be normal, and our actions revolve around normality. People compare themselves to others. To understand disability, one must return to the concept of normality, and the normal body. Davis states that:

‘...the problem is not the person with disabilities, the problem is the way that normalcy is constructed to create the ‘problem’ of the disabled person’ (quote Davis 1997, p. 9).

Disability and Stigma

In much of the literature about disability it has been assumed and concluded that people with disabilities are exposed to stigmatisation, discrimination, and sometimes even maltreatment.

Michalco (2002) writes of his own experiences as a blind person. He has written several books about his disability, but in the book ‘The Difference that Disability Makes’ (2002) much of the focus is on the social construction of disability, and how cultural assumptions and stereotypes put limitations on the lives of people with disabilities. Michalco (2002) tells his own story of suffering, a suffering connected as much to society’s construction of his disability, as to the disability itself.

It has been argued that a sense of self is born in the interplay between the external world and each individual’s internal response. Albinism is a very important part of that sense of self (NOAH-3, p. 1). A study (Wan 2003) has been done on this topic, and on individual coping-strategies. This qualitative study, conducted at Douglas Hospital Research Center in Canada, concerns experiences and coping strategies of twelve people with albinism from various (western/white) countries globally. Eight coping strategies of resistance to stigma are identified, and these, Wan (2003) states, are *‘essential elements*

of personal change and even, possibly, social change' (quote Wan 2003, p. 277). The study is framed around Goffman's theory of stigma. The objective of this study is *'...to provide an overview of the adversities that people with albinism face and the mechanisms they develop to deal with them'* (quote Wan 2003, p. 279). It is assumed that people with albinism experience stigmatization and marginalization all over the world, and the researcher set out to examine this, and how people develop coping strategies. As mentioned earlier, however, the aim of my study was to examine whether or not these phenomena were present at all, and if so; to what extent and how it affected the lives of people with albinism.

Ingstad (1995) disputes what she refers to as a generalization that has been made to draw attention to the situation of disabled people worldwide. A generalization saying that disabled people in developing countries live in *'a state of utter misery and neglect'* (quote Ingstad 1995, p. 246), resulting in what Ingstad refers to as a *'myth of the hidden disabled'* (which is the title of Ingstad's book on this subject). Ingstad argues that this is to a large extent a myth created to get political support and funding to programs giving priority to disabled people as a group in society. Ingstad disputes the myth on the basis of her own meetings, observations and conversations with these so-called *'hidden disabled'* and their families (Ingstad 1995). Out of 100 disabled persons interviewed, Ingstad was taken to eight different disabled people that were said to be hidden, neglected and abused, and the outcome was that:

'Among the eight cases that were shown to me by the rehabilitation workers as examples of hiding, neglect, or abuse, only two proved to be so to some extent when looked into closely. And even in those two families we found that the situation of the disabled person was mainly a reflection of

the general hardships that all household members were living under'
(quote Ingstad 1995, p. 252).

Ingstad's point is not that neglect and hiding do not happen, but that we must have empirical evidence for statements of hiding and neglect, and not assume that it occurs universally. Such phenomena must be seen and understood through the different context where it occurs.

Albrecht and Devlieger (1999) also refer to a myth related to people with disabilities.

'Why do many people with serious and persistent disabilities report that they experience a good or excellent quality of life when to most external observers these people seem to live an undesirable daily existence?'
(quote p. 977).

This myth talks of the notion that people with disabilities are seen to have a very poor quality of life. The authors talk of a disability paradox, referring to studies of disabled people where they were asked how they perceive their own quality of life. Most replied that they had a very good quality of life, and so the disability paradox was created.

International Agenda

In the past few decades efforts have been made on the international agenda to improve the situation for people with disabilities. With the International Year of Disabled Persons in 1981, The World Programme of Action concerning Disabled Persons in 1982, and the development of the Standard Rules on the Equalization of Opportunities for Persons with Disabilities (UN 1994), awareness was raised on the topic, and programs put into action (UN 1994).

In Malawi disability is on the agenda, and the Standard Rules were implemented with the initiation of a multi-party democracy in 1994. A report written in 1997 (Michailakis

1997) does however show that as of 1997 there was no officially recognized disability policy in Malawi, and although the government had at that stage adopted the standard rules on the equalization for people with disabilities, nothing had been done to convey the message of full participation for people with disabilities. No benefits are guaranteed by law to persons with disabilities. There is a national umbrella organization for people with disabilities; Federation of Disability Organisations in Malawi (FEDOMA), but disabled people's organizations (DPO's) are not consulted when laws and regulations with a disability aspect are being prepared. Organizations for persons with disabilities are not given any government support (Michailakis 1997). The Ministry of Social Development and People with Disabilities in Malawi was established around the turn of the century. The ministry is currently working on a national disability policy which is expected to be finalized this year. Norwegian Association of the Disabled (NAD) is supporting both the development of the ministry, and the National Disability Policy (Brodtkorb & Kisubi 2001).

A survey on living conditions among people with disabilities has been conducted in Malawi.

The survey was a collaboration between FEDOMA, Norwegian Federation of Organisations of Disabled People (FFO) and SINTEF Health Research in Norway. The survey, launched in September 2003, showed that there are systematic differences between people with and people without disabilities. People with disabilities are in many cases worse off than those without disabilities; in economic situations, schooling and job opportunities (Loeb and Eide 2004, pp. 17). It was, however, noted that people with disabilities were not much affected by their disability status in family settings (Loeb and Eide 2004, pp. 157-159).

As mentioned earlier, Malawi has an organisation for people with albinism; The Albino Association of Malawi (TAAM). This organisation is registered as a member of the Albinism World Alliance (AWA), and is also registered as a member organisation under FEDOMA. TAAM is an organisation which receives very little funding, and has limited means to ensure its success. Since its start in 1995 it has not been able to do much for its members.

Methodology and Sample

For this particular project qualitative methods were deemed suitable because the study aimed at understanding and exploring an area where previous knowledge is very limited. In this study the aim was to learn from the subjects about their views and knowledge, to explore their points of view. The study also aims to explore the phenomena of albinism in detail, and to create a broader understanding of how it is perceived in a Malawian context. Ethical approval was sought and obtained from ethical committees in both Norway and Malawi.

The **Republic of Malawi** is located in the Southern Central Africa, and has a population of about 11 million people. It is a very poor country; one of the 12 poorest in the world by UN estimates (UNAIDS 2002). After three decades of repressive one-party rule, Malawi became a democracy in 1994, with the election of President Bakili Muluzi (from the United Democratic Front; UDF), who presided for ten years. New elections were held in June 2004, with the election of the current president; President Bingu Wa Mutharika (also from UDF). English and Chichewa are official languages (World Factbook), but the literacy rate is only 58% (72, 8% for men, and 43, 4% for women) (UNAIDS 2002).

One part of this study was done in Blantyre district, while the other part was done in Mangochi district. Blantyre district is an urban district, while Mangochi district is a large, rural district. The climate is also quite different in these two districts. Blantyre is a highland district, and therefore much cooler than Mangochi district, which is mainly a low-land district. Mangochi district is to a large extent centered around Lake Malawi, and has a very tropical climate.

The study population was people with albinism, their family members, and other people otherwise involved in the lives of people with albinism. 25 people were interviewed, of them 11 people with albinism, 11 mothers of children with albinism, two siblings of people with albinism, and the leader of The Albino Association of Malawi (who is also a person with albinism). 17 interviews were done in Blantyre district, and six in Mangochi district. More interviews were conducted in Blantyre district because it was easier to find subjects there, and they were easier to access.³

The majority of the Malawian population speaks Chichewa. Since the two translators that were used could only speak English and Chichewa, all the subjects interviewed were either Chichewa or English speaking. People speaking any of the other local languages were excluded from the study. In Blantyre district all the people I met spoke Chichewa or English, while in Mangochi district approximately half the people I met were excluded from the study because they did not speak any of those languages.

Individual, in-depth interviews were conducted with all the subjects. An interview guide had been made beforehand, and the same guide was followed in all the interviews. The interviewer was the author, but in most of the interviews an interpreter was needed, as few of the subjects spoke English, and the interviewer did not speak the local language, Chichewa. 17 of the 25 interviews required the services of an interpreter. The two

³ Participation in this study was voluntary, and this was made clear to the subjects either by a participant information sheet, or orally by the interviewer. Confidentiality of all participants was assured, and they were asked to sign a consent sheet.

interpreters used were local Malawian women, and they were also people with albinism. None of them had any previous experience in interpretation, but one was a nurse, and one had data-collection experience, and works for a disability organization. They both received information from the researcher about what was expected of them as interpreters in this study.

On a 2-3 month period the researcher spent considerable time with both interpreters, and has used this time as a type of participant observation. The researcher and interpreters shared common experiences, and stories were told by the interpreters about their own experiences with albinism. The interpreters, as local Malawian women, were also able to explain and guide the researcher through every-day situations that occurred throughout the study.

‘We only believe that God created us...’

One man with albinism that I spoke to told me that people in his village looked down on him and his family, because he is a person with albinism. He said that he was the lowest rank in his village. I visited him and his family in the village once, and they invited me for lunch. After lunch the man walked me to the bus, and he told me that my visit would give him a higher rank in the village. Apparently it is of great honor to have a westerner dine in your home, and he said that he had noticed people looking at him admiringly as he was moving around in the village with me.

Similar to the myth I spoke of in the introduction (‘The origin of Albinos’), the man in the story above had experienced exclusion and hardships related to being a person with albinism.

Many factors play a role in deciding people’s quality of life. In the life of people with albinism a few factors differ from the life of an average Malawian. As mentioned earlier,

people with albinism always have problems with their eyesight, and due to the climate in Malawi, people with albinism have severe problems with their skin, sometimes so severe that it leads to skin cancer. One factor that plays a large part in the lives of all people is their relationship to other people, and this I have tried to explore in this research.

Cause/ Origin of Albinism

When asked to explain what an albino is, all, but one, were unable to answer. All were asked where the person with albinism was born; in the hospital, or at home or in the village. They were then asked what they had been told from medical personnel after the birth of a child with albinism. Not one person had received a good explanation for why a child is born with albinism. Some had been told to keep children with albinism out of the sun, while others had not been told anything.

I was told of several stories and common myths related to people with albinism, however none of those I interviewed were aware of the myth 'The Origin of Albinos' I mentioned earlier.

One mother, when asked why she thought she had a child with albinism, said that:

'Maybe it's an illness in me, that's why I gave birth to him (the child with albinism). They call it 'Mwanamphepo', I don't know what it is in English, it is an illness believed by old people, it's kind of ancestors and stuff. Other's say I might have another baby, an albino also' ((B10).

I asked a local health professional about the disease Mwanamphepo. He told me that it is a skin disease which can cause illness in new-born children if the mother has the disease when she is giving birth. He said that the disease does not cause albinism, but it is commonly believed to do so. Another person (a researcher) told me that Mwanamphepo

is not a disease as we know it in the biomedical paradigm, but rather a condition related to taboos. That is; if a pregnant woman breaks a taboo this can cause Mwanamphepo, which again can cause disease in the unborn child.

A very common myth in Malawi is that if a pregnant woman looks at a person with albinism, she will have a child with albinism herself. It is said that one way to prevent this from happening is for the pregnant woman to spit on the ground if she has looked at a person with albinism. Many people with albinism that I spoke to told me of this myth and the practice of spitting on the ground. One mother said that:

'Not much was said by other people, but when I was with him, moving somewhere else, during that time, some mother's would look at him and they would spit. They say if you look at an albino, and you don't spit, you give birth to an albino' (B07).

One person told me that he had been told that people with albinism were not really people, not humans. When asked what they were if not humans he was unable to answer. He stated that:

'People in the village think that the albinos are not people' (M20).

Other myths build on this idea, such as the myth that people with albinism do not die, or that they are ghosts:

'People regarded that anyone who has got a white child; they regard the child as a ghost. 'She has got a ghost'. Some people were even saying 'why can't you just do something so that he can die?', things like that. So I was saying to them that there's no problem, no problem, I can't do that. And if I do that, I think God will punish me' (M24).

The most common explanation for albinism that I came across with all the people that I spoke to is that of God:

'I only believe that God created us, and it can't be his intention for us to suffer each and every time, I still believe that he has something for me to do. Because of that I feel free, because of that belief I have in God I feel free. Some other friends they chat with me normally, as they chat with their fellow blacks. So that makes me to be free. Some say this or that, some bad things of us, but because of those friends, because they are kind, that makes me to feel free. Not so many times I sit and think and worry about my appearance, because I believe in God, and I believe he has something in store for me. It was his will. I didn't apply for that. So I feel free. Even if there are some other people, they say lots of bad things, but I only believe in God. Some other friends they blame them, advice them not to do that, there are some other friends who sometimes wanted to argue with them, but I say don't worry. I feel free' (B03).

This explanation, that God has a purpose, is one that I came across in many of my conversations with people with albinism and their family members. Mothers expressed things like:

'I believe that it's God who gives, and it's God who gives for your own child. So I had that love (for my daughter) despite what people were saying' (B04).

The 'language' of albinism

There are many words, both in the local languages, and in English, that are used to describe a person with albinism in Malawi. The most common name is 'Mzungu' or 'Azungu' (Plural of mzungu). These words are normally used to refer to white people, or white, western people. I, the researcher, am a white, western woman, and I experienced being called mzungu numerous times. When I moved around in Malawi with my two

interpreters, both of whom were ladies with albinism from Malawi, people commonly looked at us with great surprise, and yelled ‘azungu’ at us. One of my interpreters told me that she had overheard people commenting on the two of us, wondering what the connection was between these two white ladies who were so obviously different.

In the urban areas, where people commonly speak English, people with albinism are often referred to as ‘yellow man’, or Jeffrey Zigoma. Jeffrey Zigoma is a famous gospel singer in Malawi, and he is a person with albinism. One man told me of his reaction to being called these names:

‘They tell me that ‘mzungu’, ‘zigoma’, ‘white man’. I just say ‘of course I am a white man, but I am enjoy with my life’ (B12).

Another common name for people with albinism is ‘napwere’. The meaning of the word ‘napwere’ was explained to me by one of my interpreters, the explanation was:

‘That is dry pigeon peas, when they are dry they are kind of brownish. So I think it’s a kind of mockery name. That is the most common name’.

Family

Most parents, when asked about their reaction to having a child with albinism, expressed happiness. All the mothers talked of a great love for their children, while there were occasions when the fathers had rejected their children because they were albinos. Two siblings, both people with albinism, talked of how their father had left them. They said that he was not happy with them, and so he left the family and married another woman. He also had a child with albinism with the new woman. When asked why the father left, the daughter answered:

‘(...) He did not want to stay with us. He want to kill us, he don’t want to see people like us’ (B13).

Other fathers had also abandoned their children with albinism, believing that they could not be the fathers of such children. One single mother told me of her husband's disappearance; when the child was born, he left:

'Because he (the child) was white, he rejected him, (...) he didn't think he was his son' (B07).

Another mother had experienced similar reactions from her husband's family:

'From the father's side they were saying this is not their son's baby. (...) They thought I was having an affair with an albino, not a white, because a white would have a colored as a baby' (B05).

One mother talked of her initial surprise and frustration when she gave birth to her first child with albinism:

'I was worried, I even blamed god, that 'why did God give me this child'. I was worried that 'why me have this child, what have I done to have this child, why me?'. This was my worry. Sometimes I am confused; I don't know what causes it. Sometimes I am thinking that I have been bewitched by people, or maybe it's God. But I don't know yet, I am undecided' (M20).

Another mother also spoke of feeling surprised when she gave birth to a child with albinism. This woman was also one of the few I spoke to who had made some enquiries into why she had given birth to this child:

'When I gave birth to that son I was surprised. I was not disappointed, but I was just surprised. So I went to my parents and asked them why has this happened? Do you have any history? To both parents, my husbands's and mine, if there was any history of that, and they said no. So I was the first to have an albino. So I was not depressed, but I was surprised' (B10).

A child with albinism, as any other child, will get his or her first impulses from the parents, or the people who raise them. Among the people that I interviewed, it seems that the people with albinism who come from families with more resources, where the parents have education, these people have more faith and hopes for the future, and they also have less worries related to other people's reactions to them. One mother stated that:

'I believe that a child is God's gift, and God gives anyone whatever he has desired. And I believe that God gave me Mike and Adija for a purpose. I don't know. People were laughing at me, really laughing. And that affected me, but my husband comforted me. 'Why worry, it has got arms, eyes, legs - why worry?' And we were just living normally' (M24).

I spoke to several mothers of children with albinism, and, as mentioned above, they all spoke of a great love for their children. Several mothers told stories of other people's reactions to the child with albinism:

'People were laughing at me, that I'd had a napwere. They had never seen her; it's not in their blood to have somebody like her, so where did I get her? So it's those kinds of remarks. But they never took the love away from me' (B04).

Similarly, another mother stated that:

'I just know that albinos are human beings' (mother of albino girl, when asked if she knows what an albino is) (B04).

The brother of two girls with albinism, when asked how he sees his sisters, said that:

'There is no difference, I see them as human beings, we are all the same. They are equal to other Africans' (B06).

School/ Friends

Most of the people with albinism that I spoke to came from loving homes. As mentioned earlier, some had been abandoned by their fathers, but had still been loved and looked after by their mothers. The problems some people with albinism face are in the interaction with strangers. One woman told me that she had experienced several difficulties in her childhood, and these difficulties were connected to strangers. Her parents had treated her equally to her other siblings, and had loved her very much. From strangers, however, she experienced discrimination and difficulties:

'People do something which is bad, which is not good.(...) They spit, they spit...down on the ground. Some they don't want to see you, you are something which is not good for them.(...) Because I am an albino. (...)They will bear a child like me'(B09).

The belief that a disability is contagious has also been told of from other African settings, for example in relation to epilepsy in Botswana (Ingstad 1997).

Another person experienced problems related to appearance :

'When I grew up I was met with some problems, like my appearance. Some people judging me when I walk in. and when I stayed with my friends they just rejected me (B12).

While many people with albinism talk of experiencing strange reactions and behaviour from strangers, this bad behaviour often change as people get to know them. As one mother said:

'His friends used to laugh at him, but now they don't. At first he used to not want to go to school, because his friends would tease him, but now they don't. So now he likes going to school' (B16).

Another mother told similar stories of her children with albinism; stories of two children who have many friends, with whom they interact normally. When they move out of their normal environment, however, they often experience discrimination:

'Yes, most especially when they were young, their friends could laugh at them. But it's my children, they were not isolated. Like Mike, he has got many, many friends. Starting at a younger stage, up till now. Similarly to Adija. They play normally with their friends, they have got no problem. But if they leave here and go somewhere, and people who don't know them would say 'hah, look at that one'. But because they are used (to it), they don't see that as a very big problem, they are used (to it), they live normally. (...) When they move out it is especially small children saying things. People who haven't seen something like them are afraid of them, but for someone who's used (to seeing people with albinism) there's no problem' (M24).

Many mothers said that there is no difference to them, having a child with albinism as opposed to a black child, but one says that:

'(Other) people they tend to mock him, make him feel out of place... They say you are Mzungu; you should not play with us...He has no problem interacting with other children; it is them who have the problem. He does not feel different from other children, but they make him feel different. They call him names' (B02).

While some, like the person above, experienced being segregated from their friends, others felt accepted and loved by their friends:

'(...) I thank God. Some people segregate us, but others love all (of) us, and doing whatever they do together with us. Especially I have some friends, good friends, they do come here and chat, they chat with me as they chat with some other fellow black man.

But not so many as I see in other parts that there are some segregation. But not so much' (B03).

Most of the people that I spoke with did not see people with albinism as much different from Malawians with black skin. Part from the appearance, they mostly saw themselves, or their family members with albinism, as the same as everyone else. One lady told me that despite the fact that she sees herself as the same, strangers see her as different. I asked her how people act towards her, and she said that:

'They are afraid' (B09).

A mother told me a similar story about her son with albinism:

'Mostly his friends call him 'you are a Muzungu, you are white'. So he goes to me (the mother) and say 'they are saying I am white, am I white?' so he doesn't see any difference. He feels he is just like anyone else'(B10).

One mother of a child with albinism told me of her son's problems in school:

'(...) Some time back when he first started school, his friends were beating him, and pinching him, to see if he has blood the same as theirs. So they would beat at him so he would bleed. And so I would go to the teachers, and now it's stopped (B07).

A school teacher, who is also a person with albinism himself, told me of his observation of how the children with albinism in his school were treated:

'(...) I see some young ones, young albinos, people say lots and lots of bad things to them, segregate them, and I have been advising some of the black people that they are not to do that, to fear God, that as God created you, in the very same way he created me, people like myself. So we have to fear God. If you say some bad things on us, I can't do anything bad to you in return, only God himself, so I hope... There are some others who do not even fear God, you know, there are different types of people. But others they fear God, and they understand my advice' (B03).

Job situation

One man with albinism told me that he had experienced problems in getting a job, because many people believe that people with albinism die young. He himself did not believe in this myth, as he stated that:

'Especially what I talked about, that we have a short life (has been a problem for me). So many people they believe in that. Maybe some of the times, that's only the big problem. There are some beliefs, so for that reason they segregate us. (This) has been a problem in my life'. (...) But for me I don't believe that (we have a short life), because I have seen so many ...even of age. Some other black's they die while they are still young. So I can't believe that we don't live long, because life belongs to God himself. So nobody can judge about somebody's life. But lots and lots of things have been said from other people' (B03).

An albino lady also told me of her difficulties in getting a job, and her rejection from nursing school:

'I have difficulties, when I go for interview the boss from that job look me, they didn't take me. They say 'you can not help us', and I come back still more, I want to go to the nursing school, and when I go there they say 'you can not help us, because our medicine is too difficult for your skin' (...) I always get rejected because of my skin.' (B09).

Physical Issues

Many children with albinism experience problems in school. These problems are physical problems, such as skin problems when they play outside, or problems with vision, when they are unable to see what is written on the blackboard. Some schools have set school

uniforms for the children to wear, and these are often short sleeved. A few people told me that they were forced to wear these short sleeved uniforms, despite the fact that they had been advised by health personnel to wear long sleeved clothing. In other schools the children were allowed to wear long or short sleeves as they pleased. Some teachers made special considerations for the children with albinism, such as to let them sit close to the blackboard or to themselves write down everything from the blackboard on a note for the children to read. Those with albinism who had been to school had noticed that they had poor vision, while those who had not been to school seemed unaware of this problem.

All the people that I interviewed to knew that the skin of people with albinism is very sensitive to the sun. They knew this because they had seen it or experienced it. Very few of the people I spoke to had ever used or heard of sunscreen, but they knew that they could protect the sensitive skin with long sleeved clothing and hats. For many families this is impossible to accomplish, as the costs of such clothing is too high. One man with albinism, when asked of the sun's effect on his skin, and his knowledge about sunscreen said:

'It's like it burns. We used to put on short sleeved, but when we were advised, we tried to follow those advises. Only, I read in the magazine, from Zimbabwe, that there are some lotion, they call it sunscreen lotion, I have never seen it. Sometime I went to Lilongwe, so when I was there I was just walking in town, so someone called me and said come at such-such place, a friend from over sea gave me some lotion, so they have it. When I come there they say I met someone and gave it there. So they did not have. But since I read in magazine it seems it is a good lotion. But I have never seen it. It is never to be seen in Malawi. But it is called sunscreen lotion' (B03).

For a while, while I was in Malawi, I helped a Dutch organization distribute sunscreen to people with albinism in Mangochi district in Malawi. We visited the families of people with albinism, gave them sunscreen (the sunscreen had been collected in the Netherlands, and sent to Malawi for distribution), and explained to them how to use it. Some of those with albinism who had never used sunscreen before, we visited again after two weeks to see what effect the sunscreen had. In all the cases that we saw the skin had improved greatly after two weeks use of sunscreen, and the people with albinism reported that their skin felt much better.⁴

Discussion

There seems to be a common assumption both in literature, and in people's beliefs that people with disabilities have a poor quality of life. This also seemed to be the assumption about people with albinism in Malawi and other African settings. My aim with this study has been to examine people's quality of life, without assuming that it is necessarily bad. As mentioned earlier, Malawi is a very poor country, it is in fact said to be the poorest country in the world not affected by war. Given this fact, it would be reasonable to assume that many people in Malawi have a very poor quality of life. The majority of the Malawian population live under the poverty level, they have difficulties getting an education, a job, and therefore also have difficulties surviving on a day-to-day basis. This was also the situation for many of the people with albinism and their family members that I spoke to. I cannot, however, say that I got the impression that the quality of life for people with albinism was much worse than that of the average Malawian, taking their own perspectives as a starting point for my impression.

⁴ For more information about this sunscreen project, see: www.afrikaansealbinos.nl

The concept of normality is very important in western society. As mentioned earlier, western society can, in many ways, be seen as a bell shaped curve, where most people want to fit into the middle of the curve, to be like the majority of the population (Davis 1997). People with disabilities can often be seen as outliers on the normality curve, as can people with albinism. I made an attempt at exploring this concept of normality in Malawi, but ended up with two conflicting arguments. Some people with albinism showed evidence of trying to look more like the average Malawian. An example of this is when people with albinism dye their hair darker, or wears dark wigs. On the other hand, most of the people that I spoke to seemed to be at ease with their own situation, not trying to fight it. Many said that they believed that they had been born with albinism for a purpose, a purpose only God knows. Some of the people with albinism that I spoke to said that they do not feel any different from the average Malawian. Most had experienced being treated equally by their close family and friends, while strangers were often the ones to show actions of stigma and discrimination.

Goffman (1997) argues that social identity is based on first appearances, and occurs through mixed contacts. This I found was also the case with many of the people I interviewed. They were instantly judged by their first appearance, which is very different from that of most Malawians. In Goffman's notion of stigma, however, he sees it as a static concept. I would argue that stigma differs in different cultural settings and also in different social settings. Stigma, as I see it, is in constant flux, as argued by Coleman (1997). In many cases the instant reactions of strangers changed as they got to know the people with albinism, and found that they were not so different after all.

A stigmatised person is seen by Goffman as a victim, inferior, someone who is not quite human. The myths I have referred to earlier verify this theory. The myths refer to people

with albinism as ghosts, as not people, as causes of a disease, a curse, or as punishment from the Gods. The people I spoke to seemed to have a great respect for these myths, and believed in them unless proven wrong. I say 'proven wrong', because many people seemed less concerned about these myths when they got to know the people with albinism. Most of the people with albinism that I spoke to did not believe in these myths themselves, and neither did most of the family members I interviewed. These people simply told me that myths exist and that 'other people' (strangers) believe in them.

I have told stories of children being teased, having problems with getting an education, and later on having problems getting a job. These two problems are problems that the majority of Malawians have in common. I have also told stories of children who are loved, who play with their friends, and who believe that God has created people with albinism for a purpose. The question is: *Is stigma present or not where people with albinism in Malawi are concerned?* The answer to this question is yes and no. Stories of myths and discrimination that people with albinism experience show that stigma is present. These stories usually take place where people with albinism interact with strangers. This could be at school, in the process of applying for a job, at the market or on the street. At home, however, surrounded by family and friends who know them and love them, people with albinism do not experience stigma. They tell stories of acceptance and love, and a belief in God that gives meaning to their life, and their very special attributes.

My argument builds on the notion that stigma is a changing concept. While people with albinism in Malawi experience stigma in certain social situations, in other situations stigma is not present, and they are treated with respect and love, equally to everyone else.

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5.1 Appendices

1. Interview guide
2. Participant Information Sheet
3. Informed Consent Sheet

Interview Guide

In all the interviews will start by thanking the person for participating in the study. Tell him/ her about the study, and the conditions for his/ her participation. Show the participant the information letter, or read it to the person if he/ she is illiterate. Both participant and the researcher sign the informed consent letter, or oral consent is given on the Dictaphone if the respondent is illiterate. In the cases where a translator is used, explain to the participant the role of the translator and the role of the researcher. Ask the participant for his/ her approval for using a Dictaphone to tape the interview, and/ or for taking notes throughout the interview.

People with albinism:

1) Socio-economic/ demographic profile:

- age
- country of origin
- town where he/ she lives
- marital status
- level of education
- poverty: economic status
- job

2) Social relationships:

- How was your childhood?
- How do you think (if in any way) albinism had an impact on your childhood?
- Are they harassed: relationship to people: friends, family and strangers
- First appearances
- Jobs: in the past and now
- connection between job availability, poverty and albinism

3) Marriage and family life:

- Do they marry
- Do they have children
- Are their children harassed for having albino parent/s

4) Vision/ Eye -sight

- vision: how bad, and what affect on life
- skin problems
- what help do they get

5) Knowledge about albinism

- What do you think albinism is?
- Why do you think your skin is lighter than most people in your country?

Mothers with albino-children:

- reaction to having albino child/ children
- how was the birth: normal, not normal? (why/ why not?)
- How has other people's reactions been to you and your child?
- Reaction of other family members...especially father...
- Why do you think you got an albino child?
- Why do you think some people are born albinos?

Fathers with albino children:

- similar questions to mother

Other family members/ friends:

- ask about their relationship with the albino
- ask about their thoughts about the albino
- do they think albinism has any implications on the life of the albino? If yes; what implications?
- Does have any implications for them being related to/ friends with an albino?

Albinism in Malawi

Participant Information Sheet

I am a master student from the University of Oslo in Norway, doing a degree in International Community Health. I am currently working on my master thesis on Albinism in Malawi, with a six-month fieldwork in Malawi from July till December 2004. In that context I am interested in your views and your knowledge about albinism, and will want to conduct and interview with you on that topic. I will ask for your permission to tape-record the interview, and to take some notes along the way. You are free to refuse any of these requests without prejudice.

Some of the questions may be too personal, or you may be unable to answer them for other reasons. You are free to answer or not answer whichever questions you like. If you at any point wish to terminate the interview, this will be done without any questions or prejudice. If you at any time wish to withdraw from this study, even after the interview is conducted, you are free to do so.

All the information obtained in this interview will be kept confidential, and your name will not be used at any point. Any questions you have about this study can be directed at the researcher (see contact detailed below).

A summary of the finished results can be provided at your request.

Thank you for considering participating in this study.

Researcher

Stine Hellum Braathen

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Supervisor

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Albinism in Malawi

Informed Consent

I (the informant) _____ agree to the conditions as stated in the Participant Information Sheet. I am aware of the fact that I am participating in this study on a strictly volunteer basis, and that I can withdraw at any time.

I (the researcher), Stine Hellum Braathen, promise to keep the informant anonymous, and not refer to or use his/ her name or picture (if relevant) without his/ her consent.

Informant Signature
(Signed by guardian if informant is below legal age)

Researcher Signature