

Albinism in Malawi: knowledge and beliefs from an African setting

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This article is based on a qualitative project which has set out to examine knowledge, beliefs and behaviour related to people living with albinism in Malawi. Individual, in-depth interviews were carried out with 25 people with albinism and their family members. The findings show that most people with albinism, as well as their families, have very little knowledge about albinism, but many know and experience that the skin of people with albinism 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 albinism. 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.

Introduction

In a book of oral literature from Malawi an old myth has been described (Schoffeleers & Roscoe, 1985, pp. 106–108). The myth does not seem to commonly exist in today's Malawian society; but it does show that the concept of albinism has existed for a long time in Malawian culture, 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. 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

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that her husband now had a 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. 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.¹ Not many studies have been carried out on the social aspects of albinism in Africa or elsewhere, there is no current scientific literature available about albinism in Malawi, and no previous research in the field of albinism in Malawi currently exists.

This study contributes to the existing knowledge and literature of disability and stigma by focusing on a disability that is more visible on the surface than it is physically and mentally limiting. Thus it may contribute to our awareness of what visual appearance means cross-culturally; as a disabling trait in one end of a continuum, to respect and perhaps even holiness in the other end. This is similar to obesity in the modern world, which is increasingly being seen as a disability and a fault of character, while it in many African societies is seen as a sign of well-being and wealth. The study also contributes to the understanding of a visual trait in a social context. What may be considered and treated as a stigma in one context, for instance in public life or in relation to job-seeking, may not be so in the family and local community where people know each other as whole persons, and kinship and personal characteristics become more important than looks.

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. 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 dark skinned. Furthermore, the majority of the population in Malawi and other African countries is uneducated, and there is an enormous lack of awareness about albinism in particular, and about disability in general. Malawi has a tropical climate, and the strong sun can be a severe burden for the skin of people with albinism. This problem is magnified in a country like Malawi where sunscreen lotion is practically unavailable, or unaffordable for the local population.

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. No such assumptions were made in the preparations for this study. 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.

Background

Albinism

Albinism is a genetic, inherited condition, caused by a recessive gene that occurs in all populations; humans as well as animals. A person with albinism has little or no eye-, skin- or hair pigment, and is often burdened with sensitive skin and low vision.

In tropical countries it is not uncommon for them to develop life-threatening skin cancers if they do not use skin protection (sunscreens rated 20 or higher) (NOAH, n.d.). The prevalence of albinism differs from one country to another. It has been estimated that in the USA one person in 17,000 has some type of albinism (Wan, 2003, p. 277). Studies from Zimbabwe and South Africa, however, show that the prevalence of albinism in these countries is approximately one in 4000 (Lund, 2001; Lund & Gaigher, 2002). The prevalence of albinism in Malawi is unknown, but it is expected to be similar to that of other African countries.

Malawi

The Republic of Malawi is located in Southern Central Africa and has a population of about 12 million people (*The World Factbook*, 2005). 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. English and Chichewa are official languages (*The World Factbook*, 2005), but the literacy rate is only 58% (73% for men and about 43–44% for women) (UNAIDS, 2002).

Stigma

A stigma is a special kind of relationship between attribute and stereotype. (Goffman 1997, p. 204)

Stigma has been a central concept in this project, and has for the purposes of this project been rationalized according 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 stigmatized person as someone who possesses undesirable characteristics that are not within the normal characteristics in the category to which he belongs. This person is thus reduced in the minds of society from a whole and normal person to a tainted, discounted one. 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 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' (Davis, 1997, p. 9). 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 those stigmatized are in contact with 'normals'. Our anticipation of others, our assumption as to what the person is like, is often based on these first appearances (Goffman, 1997).

Parker and Aggelton (2003) argue that Goffman sees stigma as a culturally constructed but static characteristic, and that this is how the concept has been used in several studies in the past. They argue that stigma is a social process under constant change, and that it is constructed, 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 to social and structural inequalities (Parker & Aggelton, 2003).

In much of the current literature about disability it has been assumed and concluded that people with disabilities are exposed to stigmatization, discrimination and sometimes even maltreatment. 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 claiming that disabled people in developing countries live in 'a state of utter misery and neglect' (Ingstad, 1995, p. 246), resulting in what Ingstad refers to as a 'myth of the hidden disabled'. Ingstad argues that this is to a large extent a myth created to get political support and funding to programmes 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. Her 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 contexts where they occur (Ingstad, 1995).

Wan (2003) conducted a study on the topic of albinism and stigma, and individual coping strategies. This qualitative study covered experiences and coping strategies of 12 people with albinism from various (western/Caucasian) countries globally. The study was framed around Goffman's theory of stigma. The objective of the study was '...to provide an overview of the adversities that people with albinism face and the mechanisms they develop to deal with them' (Wan, 2003, p. 279). It was assumed that people with albinism experience stigmatization and marginalization all over the world. The researcher set out to examine this, and how people develop coping strategies. The results from the study did in fact show that the people interviewed were exposed to stigma in many areas of their lives, but all of them said that the family setting was a 'safe heaven', where they felt loved and accepted (Wan, 2003, p. 284).

The study by Wan (2003) and this study from Malawi were carried out in two very different cultural settings. Wan's study was conducted in countries where the majority of the population have the same skin colour as people with albinism, where educational levels are high and the economy is good. In these countries most people are aware of the biological reasons for albinism; they can afford skin protection and any other special aids they might need to function well on a day-to-day basis. People with albinism in Africa, however, live in settings where the majority of the population is black, uneducated and poor. Most people do not know what albinism is, and have neither access to, nor can afford skin protection or visual aids. Regardless of this,

some similarities can be found in the results from the two studies, and these will be described further in the discussion section of this article.

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 (UN, 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 programmes 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 (Michailakis, 1997). The recently established Ministry of Social Development and People with Disabilities in Malawi has developed a national disability policy, which was finalized in 2005.

A survey on living conditions among people with disabilities was conducted in Malawi in 2003–2004. The survey was a collaboration between the Federation of Disability Organisations of Malawi (FEDOMA), the Norwegian Federation of Organisations of Disabled People (FFO) and SINTEF Health Research in Norway. The survey, finalized in September 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 & Eide, 2004, p. 17). It was, however, noted that people with disabilities were not much affected by their disability status in family settings (pp. 157–159).

Malawi has an organization 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 organization under FEDOMA. TAAM receives very little funding, has limited means to ensure its success and, since its inception in 1995, has not been able to offer 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. The aim was to learn from the people affected by albinism themselves about their views and knowledge, to explore the phenomena of albinism in detail and to create a broader understanding of how it is perceived in a Malawian context.

The study population was people with albinism, their family members and other people otherwise involved in their lives. Twenty-five people were interviewed, of these 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).² The majority of the Malawian population speak Chichewa, but there are also other commonly spoken local languages. 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.

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 first author of this article (SHB) was the interviewer, but 17 of the 25 interviews required the services of an interpreter. The two interpreters used were local Malawian women, and they were also people with albinism. Neither had any previous experience in interpretation; one was a nurse, and one had data-collection experience and works for a disability organization.

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

Similar to the myth described in the introduction, many people with albinism in Malawi have experienced exclusion and hardships related to having albinism. Several factors play a role in deciding people’s quality of life. In the lives 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 skin problems, sometimes so severe that the result is skin cancer. One factor that plays a large part in the lives of all people is their relationship to other people, and that is mainly what this study has tried to explore.

Cause/origin of albinism

When asked to explain what albinism is, all but one was unable to answer. All were asked whether the person with albinism was born in the hospital, 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 that had made sense to them. Some had been told to keep their children with albinism out of the sun, while others had not been told anything.

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 Some people say I might have another baby, an albino also. (B10)³

A local health worker explained that the disease *mwanamphepo* 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, to his knowledge, cause albinism, but it is commonly believed to do so. Another person (a social researcher) said 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 spoke of this myth and the practice of spitting on the ground. One mother of a boy with albinism said that:

Not much was said by other people, but when I was with him ... 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)

It is a very common belief in many African ethnomedical systems that disability is contagious; this has also been referred to in relation to epilepsy in Botswana by Ingstad (1997).

One person said that he had been told that people with albinism were not really people, not humans. Other beliefs build on this idea, such as the myth that people with albinism do not die, or that they are ghosts:

People regard ... a white child ... as 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 ... I can't do that. And if I do that, I think God will punish me. (M24)

The most common explanation for albinism throughout this study was that of God's will:

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. ... It was his will. I didn't apply for that (to have albinism), so I feel free. (B03)

This explanation, that God has a purpose, is one that came up in many conversations with people with albinism and their family members.

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 of western origin. Not unexpectedly, the researcher, a white, western woman, experienced being called 'mzungu' numerous times. It was noted, moreover, that the interpreters, both of whom were Malawian ladies with albinism, were also referred to as 'mzungu'. One of the interpreters said that she had overheard people commenting on them, wondering what connection there was between these 'white ladies' who were so obviously different.

'Mzungu', on the one hand, implies someone who is privileged and of high status in society, and on the other hand it is used to describe people with albinism; people who are not commonly seen as either privileged or of high status. The meaning of 'mzungu' differs in different social settings, and according to whom it is used to describe. More than anything else, the meaning of the word represents 'something

different', and the 'something different' is the white skin colour in a country where the majority of the population is dark-skinned.

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

They (call) me 'mzungu', 'Zigoma', 'white man'. I just say 'of course I am a white man, but I am enjoying my life. (B12)

Another common name for people with albinism is 'napwere'. Napwere is a type of pea, which when dry is light brownish in colour, and very wrinkly.

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, though there were occasions when a father had rejected a child because of albinism. Two siblings, both 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 wanted to kill us; he didn't want to see people like us. (B13)

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)

Other fathers had also abandoned their children with albinism for the same reason.

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; 'why did God give me this child ... what have I done to have this child ...?. 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. (M20)

As mentioned above, mothers of children with albinism all spoke of a great love for their children, but many told stories of strangers' reactions to the child with albinism:

People were laughing at me because I'd had a napwere. ... It's not in their blood (genes) 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)

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

Social settings

Most of the people with albinism in this study came from loving homes. The problems many people with albinism face are in their interaction with strangers. One woman said 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 ... on the ground. They don't want to see you; you are something which is not good for them. (If they look upon me they think) because I am an albino ... they will bear a child like me. (B09)

While many people with albinism speak of the negative reactions and behaviour from strangers, this often changes as they become better acquainted with people. One mother told of her children with albinism; two children who have many friends, with whom they interact normally. When they move out of their normal environment, however, they often experience stigmatization:

When they were young, their friends would laugh at them. But ... they were not isolated. (My son and daughter) have many friends. They play normally with their friends, and they have no problem. But if they leave here and go somewhere ... people who don't know them would say 'ah, look at that one'. But because they are used (to it), they don't see that as a very big problem ... they live normally. ... When they go out usually small children are saying things like that. 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)

Most of those interviewed in this study did not perceive people with albinism as much different from Malawians with black skin. Apart from appearance, they saw themselves, or their family members with albinism, as the same as everyone else. One lady said that despite the fact that she sees herself as the same, strangers see her as different. A mother told a similar story about her son with albinism:

Mostly his friends call 'you are Mzungu, you are white'. So he comes to me (the mother) and says; '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)

Job situation

One man with albinism said that he had experienced problems 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:

Many people believe that we have a short life. ... Some of the times, that's the big problem. ... But for me I don't believe that (we have a short life), because I have seen so many ... of (older) 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 (B03)

A lady with albinism also told 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 looks at me; they didn't take (hire) me. ... 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 and adults with albinism experience problems related to physical attributes, such as skin problems due to the sun, or problems with poor vision. Some schools require children to wear school uniforms, and these are often short-sleeved. A few people said 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. With respect to visual problems, some teachers made special considerations for the children with albinism, allowing them to sit nearer to the blackboard or to themselves write everything from the blackboard onto a note for the children to read.

Most of those interviewed knew that the skin of people with albinism is very sensitive to the sun. They knew this because they had seen or experienced it. Very few of them had ever used or heard of sunscreen, but they knew that they could protect the sensitive skin with protective clothing and hats. For many families this represents an added expense that is difficult (sometimes impossible) to bear. 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-sleeves, but (because of the sun) we were advised (to put on long-sleeves), (and) we tried to follow those advises. I read in a magazine, from Zimbabwe, that there is some lotion, they call it sunscreen lotion, I have never seen it. ... Since I read in magazine, it seems it is a good lotion. But I have never seen it ... in Malawi. (B03)

Sunscreen can have a great affect on the skin of people with albinism; it prevents sunburn (if they use sunscreen with an SPF of 20 or above), and can also help prevent skin cancer.

Discussion

Two main conclusions can be drawn from the results of this study. First, there is a dramatic lack of awareness among all the people interviewed in relation to the causes of albinism, the needs of people with albinism and the consequences of albinism for the people born with the condition. Second, there is a lack of availability of special aids, such as sunscreen and visual aids, which are crucial to the betterment of the lives of people with albinism.

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 and are the subjects of myths and discrimination in relation to their disability. This study also came across such stories, and in some social settings these phenomena were present. The aim of this study, however, 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, and is 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 below the poverty level; they have difficulties obtaining 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. It cannot, however, be maintained on the basis of the findings presented here, that the quality of life for people with albinism is much worse than that of the average Malawian.

Goffman (1997) argues that social identity is based on first appearances and occurs through mixed contacts. This was also the case with many of the people interviewed in this study. They were instantly judged by their appearance, which is very different from that of most Malawians. In many cases the instant reactions of strangers changed as they got to know the people with albinism, and found that, as individuals, they were not so different after all.

Though easy to spot, many people in Malawi have never seen a person with albinism, due to the low prevalence. The fact that people with albinism are underrepresented in Malawian society creates a greater lack of awareness. The only way to rationalize and justify what people perceive as 'an oddity' is to associate it with something which they are familiar. This could be where names and expressions like 'mzungu', 'Jeffrey Zigoma', 'napwere' and 'Yellow Man' originate. These terms all represent known people and things that, on the surface, may 'resemble' people with albinism, and simplify the association with something unknown or unfamiliar. When 'mzungu' was used in relation to people with albinism, the association it established did not go beyond that of the skin colour. While 'mzungu' in Malawi means westerner (Lane, 1995), and to many Malawians this is synonymous to a Caucasian person; someone superior, with high status; this was not the case with people with albinism. Here 'mzungu' referred to a stranger, or one that, because of albinism, did not belong in that particular society.

Some Malawians have never seen a westerner or the singer Jeffrey Zigoma, and they may, therefore, not have anything familiar to associate when they see a person with albinism. For these people, religion or traditional beliefs may seem to provide logical explanations for what albinism is, and how a person with albinism comes to be. An example of this is when people use God as an explanation, or when they refer to common myths or beliefs with which they are familiar.

The physical problems of people with albinism in this study have two components. The first is the lack of availability of protective clothing, sunscreen and visual aids, and the second is lack of knowledge of what special aids people with albinism need in order to function well in everyday life. Some people simply do not know that the skin of people with albinism is sensitive to the sun, and some people with albinism do not know that it is the sun which causes their skin to hurt and burn. Similarly, some people with albinism do not realize that they have poor vision; they are unaware of this physical limitation, and that others have better vision or that their own vision could be improved. For those who were aware of these limitations, most did not know what to do to protect themselves or improve their vision. Very few had heard of sunscreen and

visual aids, and neither medical nor traditional health workers had told them of the existence of such aids. Most people with albinism in this study had been in contact with a health worker at some point in their life. This could be a doctor, nurse, medical assistant, traditional birth attendant, etc. As part of a plan to raise awareness and provide for the needs of people with albinism, these health workers should be targeted, and encouraged to disseminate their knowledge to those with albinism whom they come across in their professions. However, to educate and bring awareness to health workers, one must first create this awareness at the governmental level, in order that the special situation of people with albinism is added into the relevant programmes.

In Malawi today, even if people with albinism knew what they needed, they would most likely not be able to get it. Visual aids and sunscreen are practically non-existent in Malawi, and in the few places where they are available, they are so expensive that they are economically unavailable to the majority of those who need them. Some parents had been told to put long-sleeved clothing and hats on their children with albinism, but to buy these clothes was not economically possible for most families. Those who develop skin cancer have to go to South Africa for treatment, which normally would only be available for the elite in Malawian society. Sunscreen and visual aids should be made affordable and available to people with albinism in the same manner as wheelchairs and crutches are available to people with physical disabilities.

To conclude that stigma does or does not occur in the lives of people with albinism would be wrong in relation to the data presented from this study. What we have seen is that in some social situations people with albinism are exposed to discrimination as a result of stigma, whereas in other social situations they are treated with respect and dignity like anyone else. Both in this study and in the study by Wan (2003), the people interviewed explained that they often experienced negative reactions and stigmatization from strangers, while in familiar settings, especially within the family, they felt accepted and included. This was also found in the results of the living conditions survey among people with disabilities in Malawi, but in this case in relation to all people with disabilities (Loeb & Eide, 2004, pp. 157–159).

There is an important link between availability of aids and awareness. Awareness can create an understanding of people with albinism, of what albinism is, and what those with albinism need to function well. It can also create a greater respect for people with albinism, and knowledge that they are, under the surface, not so different. It is important to understand their needs, and to realize that they can contribute in society alongside a Malawian born with pigment. Once this realization is made it will be easier to fight for the rights of people with albinism – not only their rights for aid, assistance and protection but also their basic human rights. Not unlike Martin Luther King Jr.'s dream for his children in fighting for civil rights in the USA in the 1960s, people with albinism in Malawi today also have the right to be included in society, 'not to be judged by the colour of their skin but by the content of their character' (King, 1963).

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Notes

1. This study was conducted as a partial completion of a Master's degree in International Community Health.
2. 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.
3. All quotes are transcribed directly from the respondent. Some minor changes have been made to make these more comprehensible to the reader.

References

- Davis, L. J. (1997) Constructing normalcy, in: L. J. Davis (Ed.) *The disability studies reader* (New York, Routledge).
- Goffman, E. (1963) *Stigma: notes on the management of spoiled identity* (London, Penguin Books).
- Goffman, E. (1997) Selections from stigma, in: L. J. Davis (Ed.) *The disability studies reader* (New York, Routledge).
- Ingstad, B. (1995) Mpho ya Modimo – a gift from God: perspectives on 'attitudes' toward disabled persons, in: B. Ingstad & S. R. Whyte (Eds) *Disability and culture* (Berkeley, CA, University of California Press).
- Ingstad, B. (1997) *Community-based rehabilitation in Botswana: the myth of the hidden disabled* (Lewiston, NY, The Edwin Mellen Press).
- King, M. L. Jr. (1963) Speech at civil rights demonstration, Washington, DC.
- Lane, S. S. (1995) *Among the wild Azungu* (Blantyre, Rightwrite Press).
- Loeb, M. & Eide, A. (2004) Living conditions among people with activity limitations in Malawi: a national representative study (STF78 A0445110) (Oslo, SINTEF Unimed Health & Rehabilitation).
- Lund, P. M. (2001) Health and education of children with albinism in Zimbabwe, *Health Education Research*, 16(1), 1–7.
- Lund, P. M. & Gaigher, R. (2002) A health intervention programme for children with albinism at a special school in South Africa, *Health Education Research*, 17(3), 365–372.
- Michailakis, D. (1997) *Government implementation of the standard rules as seen by member organizations of Disabled Peoples' International – DPI: Malawi* (Stockholm, Independent Living Institute, Disabled Persons Association in Malawi). Available online at: http://www.independentliving.org/standardrules/DPI_Answers/Malawi.html (accessed 11 December 2003).
- National Organization for Albinism and Hypopigmentation (NOAH) (n.d.) *What is albinism?* (East Hampstead, NH, NOAH). Available online at: <http://www.albinism.org> (accessed 17 February 2004).
- Parker, R. & Aggleton, P. (2003) HIV and AIDS-related stigma and discrimination: a conceptual framework and implications for action, *Social Science & Medicine*, 57, 13–24.
- Schoffeleers, J. M. & Roscoe, A. A. (1985) *Land of fire, oral literature from Malawi* (Limbe, Popular Publications).
- The World Factbook* (2005) Available online at: <http://www.cia.gov/cia/publications/factbook/> (accessed 4 January 2005).
- United Nations (1994) *The standard rules on the equalization of opportunities for persons with disabilities* (New York, United Nations).
- United Nations/General Assembly (1982) *World programme of action concerning disabled persons (A/RES/37/52)* (New York, United Nations).
- UNAIDS (2002) *Global AIDS interfaith alliance: fact sheet on Malawi*. Available online at: <http://www.thegaia.org> (accessed 17 February 2004).
- Wan, N. (2003) Orange in a world of apples: the voices of albinism, *Disability & Society*, 18(3), 277–296.

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