

Project title

An investigation into the impact of stigma on the education and life opportunities available to children and young people with albinism in Tanzania and Uganda

FIRAH code: AP2014_47

Funded by

FIRAH (International Foundation of Applied Disability Research)

Lead

Coventry University, UK

UK Partners

Advantage Africa (Uganda) and Standing Voice (Tanzania)

Partner in Uganda

Source of the Nile Union of Persons with Albinism (SNUPA)

Partner in Tanzania

New Light Children Center Organization (NELICO)

Project leader (Coventry University)

Dr Patricia Lund p.lund@coventry.ac.uk

Scientific Summary

An investigation into the impact of stigma on the education and life opportunities available to children and young people with albinism in Tanzania and Uganda

Patricia Lund and Simon Goodman, Coventry University

Albinism in Africa

Children in African communities born with oculocutaneous albinism look significantly different to their peers due to the lack of melanin pigment in their hair, skin and eyes – leading to light coloured hair, blue/hazel eyes and pale skin which is very sensitive to the damaging effects of the sun. Albinism also affects eyesight including involuntary nystagmus, photophobia, poor depth perception, strabismus (squint), poor visual acuity and refractive errors.

Oculocutaneous albinism is an inherited condition which, if not understood or managed correctly, can have significant health and social impacts on the lives of those affected. These impacts are particularly acute in regions of the world where myths and superstitions surrounding the condition can lead to stigmatisation, discrimination, rejection, misconception, and, in some cases, violent assault and murder.

This study was conducted at a time of danger as those with albinism in parts of Africa are targeted for their body parts, from hair to whole limbs, for use in witchcraft-related rituals and charms. These are mistakenly believed to bring easy wealth and good fortune. Issues of albinism in Africa are steeped in negativity and much has been written in both national and international media reports about the attacks on people with albinism and the challenges they face in Africa, both in terms of their personal security and health, with a significant risk of developing skin cancer. In the context of these attacks on those with albinism, this project aimed to document, in a positive way, the innovative and practical ways in which those with albinism navigate the many challenges they face in accessing appropriate health, education and welfare services. This fills a crucial gap in our understanding and provides the evidence base to inform interventions by both governmental and non-governmental agencies.

Foreword from stakeholders

Uganda

Jane Betts, Advantage Africa

The Ugandan element of this research was facilitated by the Source of the Nile Union of Persons with Albinism (SNUPA) working in partnership with Advantage Africa. SNUPA is a Ugandan non-governmental organisation formed in 2012, by and for persons with albinism in Busoga sub-region and its neighbouring districts. SNUPA aims to change attitudes and improve life for

people with albinism and their families. Advantage Africa is a UK-based non-governmental organisation founded in 2002 which supports people affected by poverty, disability and HIV in East Africa. In 2013, SNUPA and Advantage Africa began working together to help people with albinism to stay safe from cancer, attend school, earn an income and overcome discrimination and lack of opportunity.

SNUPA's team, composed of grassroots outreach workers relatively new to research, undertook intensive training at the start of this project in order to develop effective facilitation and interview techniques. This training and subsequent sessions to monitor the research's progress provided invaluable benefits in confidence and team-building. Through the focus group discussions, the SNUPA team have worked closely with people with albinism and their families in eight communities in the Busoga region of eastern Uganda. The fact that all but one of the team have albinism themselves, and that they are not professional researchers, has enabled them to establish a comfortable, mutually trusting atmosphere when meeting with participants. SNUPA team leader Peter Ogik in particular has helped participants feel valued and part of a unified, positive process to bring change in the lives of people with albinism.

The people who took part in the discussions told SNUPA how much they appreciated the opportunity to tell their stories and meet with others in similar circumstances. Many had previously felt isolated and marginalised, but discovered a shared sense of purpose and friendship with their peers. The participants across the region shared their experiences with generosity and openness. SNUPA and Advantage Africa will ensure that their contribution continues to be valued and they are fully included in the ongoing dissemination process.

The research's wide regional scope has enabled SNUPA to interact with new people with albinism. Therefore, alongside the research activities, SNUPA has been able to offer practical support as needed, including protection from skin cancer. All SNUPA and Advantage Africa team members have been highly motivated and committed throughout this project, driven by the goal of developing evidence-based recommendations and tools to improve the lives of people with albinism. The team will harness the enthusiasm and engagement of all stakeholders involved over the course of the project to widely disseminate these results and ensure the recommendations are implemented.

Tanzania

Jon Beale, Standing Voice

This research project has revealed fundamental learnings for achieving social change, learnings which have been illustrated by people with albinism and their communities in response to identified social challenges. It is perhaps with these learnings in the forefront of our minds that we should consider the research findings, in a bid to ensure we achieve tangible impact.

One of pronounced demonstrations of the research is the far-reaching constellation of individuals who define the life experience of people with albinism. This constellation consists of local, national and international stakeholders – ranging from family members and neighbours to key influencers in multi-lateral agencies. Understanding the importance of this social constellation is key to comprehending how we must collectively apply these research findings. The transcript material demonstrates the impact of an individual being surrounded by a supportive network of individuals, with them at the centre. Crucially the research participants emphasize repeatedly how it is the person at the centre of this constellation who has the most impact on how these surrounding people effect the present moment and future social reality of the individual. Both people with and without albinism who participated in FGDs and interviews demonstrated how the sphere of influence of an individual with the condition was far greater than may be assumed.

This learning is of the utmost importance. We have a responsibility to respect that people with albinism have the right to be the centre of influence on their individual social constellation. Participants have spoken of their need to be listened to and have their voice heard. ‘Nothing for us without us’ is a common expression that has surfaced in the transcripts in numerous different forms. Taking this on board when considering social application of the research findings means that people with albinism are true agents in the social changes we collectively hope to affect.

The second learning of vital importance when reading into the findings is that there is indeed a network of individuals who need to be worked with when implementing the research recommendations. The transcripts reveal how this network is not simply a static matrix of individual entities operating unilaterally, but rather there is a constant process of influence at play within that social fabric.

These key learnings can be considered as navigation aids for us as stakeholders tasked with applying this research. The challenges which surface in the research are associated with proactive solutions which react to and anticipate the experiences of people with albinism, based on evidence-based findings. These solutions feature in the project ‘Recommendations’, primarily generated by members of the Tanzania Albinism Society (TAS). These recommendations are not end points in our journeys, but rather actions to aim for that will require constant reassessment and evaluation.

In using these findings to continue our journeys towards the goal of true social inclusion for people with albinism in Africa, we should be reminded of our research participants who emphasized the powerful influence different stakeholders can have on their lives whilst keeping in mind the fact that only people with albinism are able to define who these stakeholders should be and how they should act. If we are to truly take this research on board as coalitions and individuals, we will understand that it is only by promoting people with albinism as centres of influence in their own right that we achieve true social change. This research seeks to platform the voice of these

individuals, so we may respond accordingly in fellowship and with respect for people with albinism as agents of change.

Methodology

This participant-led study used qualitative methods including focus group discussions and in-depth interviews in the vernacular languages to answer the research question:

How can survival from birth, educational integration and subsequent life opportunities be enhanced through an understanding of the barriers and facilitators that influence successful transition of children with albinism into education, from primary to secondary level, and into work?

The transcripts were audio recoded, translated and transcribed, and analysed using thematic techniques to unpack meanings and experiences surrounding albinism. This allows for a detailed understanding of the key issues, concerns and experiences of those with albinism, their families and their communities.

Study sites

In Uganda the study took place in districts within the Busoga sub-Region; this is one of the poorest regions of the country with a largely rural population leading a hand-to-mouth existence. In Tanzania the study sites were in the Geita and Ukerewe districts in the Lake Zone where security issues for those with albinism are particularly pronounced.

The Ugandan focus group discussions and interviews were conducted by Peter Ogik of SNUPA (Source of the Nile Union of Persons with Albinism) and Fazira Kawuma, supported by Jane and Andrew Betts of the UK based charity Advantage Africa. Local researchers, Eddy Kennedy and William Jonan of NELICO (New Light Children Center Organisation) and a team from the UK based charity Standing Voice led by Jon Beale and Jamie Walling facilitated the research in Tanzania. The Coventry based team comprised Patricia Lund (principal investigator), Anita Franklin who lead the literature review and Simon Goodman, an independent analyst who was not directly involved in data collection. All members of the team involved in the research contributed to the final analysis.

Study populations

A total of 66 participants in Uganda and 101 in Tanzania expressed their views on albinism. These included those with albinism, family members, friends, neighbours as well as (in Uganda) stakeholders such as journalists, a dermatologist, and organisations supporting the human rights of those with albinism.

Summary of the findings and outputs

The project produced rich narratives from both countries, identifying the multiple agents and facilitators helping to provide a supportive network for families with albinism, with the affected person at the centre as an active agent in promoting their own advocacy. A theme running throughout the narratives is the importance of self acceptance by those with albinism, bolstering self confidence and leading to success. There was evidence of

attitudes to those with albinism changing in a positive way as a result of many initiatives to raise awareness and provide information on albinism. From the Tanzanian narratives it was clear that this was a slow process, requiring time, with examples of those with albinism persisting in educating their communities about albinism and engaging with their friends and neighbours to gain acceptance.

A striking point of the research was the importance of single individuals in helping to break the cycle of discrimination and downward cycle of despair. One person can make a key difference in the life of a person with albinism. As may be expected, the support of family is crucial, with fathers often rejecting and abandoning the mother and child with albinism. Indications of understanding and support from teachers, pastors, neighbours, friends and, most importantly, potential employers can make a pivotal difference in the transition of a person with albinism as they move through education to gaining appropriate employment and finding a partner and starting a family.

Given the very strong evidence that economic success is crucial to the lives of those with albinism, further exploration of ways in which job prospects can be improved for people with albinism, in terms of equality of opportunity or even positive selection for those with albinism would help inform appropriate interventions. The misperception that the skin of those with albinism is 'weak', meaning that they cannot do routine manual chores such as working in a flour mill, needs to be challenged. The more damaging mistaken belief that they cannot achieve 'anything' is being discounted as more and more people with albinism take up jobs and positions in society and provide evidence to the contrary.

This research identified a gender difference in marriage prospects for those with albinism which requires further investigation; one woman with albinism commented *men seduce me but I cannot maintain a relationship*. Men with albinism usually marry women without albinism. If they have economic stability that will attract a partner. Women with albinism find it harder to find partners because they cannot bring that economic power to a marriage.

There are numerous cases of positive role models among those with albinism and those around them. These illustrative case studies, show how individuals have gained success and recognition, be it through showing initiative in thwarting an attempted abduction, or persisting in training as a tailor despite being mocked when they could not see to thread a needle.

In collaboration with participants and other actors, the team have developed a series of recommendations at different tiers, listing specific action points to be taken at different levels from national government, through local government in conjunction with the community and including calls to those with albinism themselves to be encouraged to put themselves up for positions in the community.

Outputs from this study include a booklet for children developed by Patricia Lund with images by Teresa Robertson which has been translated into Swahili and is available [here](#). They also include a series of evidence based comic strips by the Tanzanian artist Theophil Reginald Mnyavanu for use on

multiple platforms to raise awareness, and a film shot by Hamidu Ramadhan documenting the final dissemination event in Tanzania.

The importance of reporting the findings of the research back to the participants and local communities is paramount, as is the presence of local officials at the final dissemination events in both countries when families with albinism could see their voices being considered seriously.

The team have used the findings to develop a *Call to Action*, for all stakeholders to work collaboratively to act on the research findings and improve the lives of those with albinism.

The impact of albinism in the Ugandan and Tanzanian communities studied

The analysis has highlighted a range of factors that influence the lives of people with albinism. Prejudice and discrimination is common, with a high prevalence of myths and misconceptions about people with albinism. This had an impact on their school education as well as health implications. On the positive side, the role of government, non-governmental organisations (NGOs) and other agencies in supporting families with albinism, and the belief in God are shown to facilitate support for these families.

Each of these factors consists of events and experiences that can be seen to affect the lives of people with albinism in positive and negative ways.

Prejudice and discrimination towards People with Albinism (PWA)

A major theme of the lives of people with albinism (PWA) in the rural regions that were the study sites in both Uganda and Tanzania, is the large amount of prejudice and discrimination that they face.

Rejection from family

- A major part of the life experience of PWA is being rejected by those around them, including from very close family members. Fathers often leave their children with albinism and their wives on the birth of a child with albinism. In other documented cases, despite pressure on partners of PWA to leave their families, they often defy this pressure and stay by their side
- Pressure on partners or parents of PWA to leave their families
- Partners often defy prejudice to stay with people with albinism despite any difficulties this may create for them

Fear of people with albinism, which leads to isolation

PWA are often feared by the wider community in rural areas, including fear of physical contact with them. This leads to isolation and perpetuates the cycle of discrimination of PWA. Much of this isolation is imposed by others, but the fear of attacks means that PWA may choose to isolate themselves or their

children with albinism. In addition, others outside the family avoid PWA, so PWA come to be marginalised.

Fear and threat of attacks

As a result of the attacks against PWA because of an interest in their body parts, PWA, and their family members, live in constant fear of being attacked or kidnapped.

Name calling

As part of the wider discrimination that PWA experience, they experience name calling and bullying on a regular basis. This often occurs at school or college, but also in other areas of life.

Discrimination at school

In addition to experiencing bullying at school, PWA can under-perform if their visual impairment is not recognised and teachers do not make adjustments to accommodate them in the classroom environment.

Support from friends, family and teachers helps to overcome this discrimination.

Hard to get jobs

The widespread discrimination towards PWA makes it difficult to get jobs. Ideally those with albinism should have indoor jobs to limit their daily sun exposure. The risks to their security means that they cannot work in isolated areas, such as tending their fields. In communities which rely largely on subsistence farming this imposes difficulties in feeding families.

Hard to find a partner and to marry

This includes discrimination from the family of potential partners, who do not want to accept a PWA.

The prevalence and problems of myths and beliefs about PWA

A major feature of the interviews was the prevalence of myths about PWA in Uganda. These myths are particularly damaging and need to be challenged. Fear of the witchdoctors and traditional practitioners was often mentioned by those in both countries; they are viewed as instrumental in the trade of the body parts of PWA, and seen as a major threat, especially regarding the risk of being kidnapped or harmed. There was particular interest in the hair of PWA in Uganda, leading to abuse of young people with albinism as their hair is forcibly cut off. Fear of attack and abuse restricts the movement of PWA, especially at night.

Range of myths about albinism

The myths contribute to the discrimination towards, and isolation of, PWA and demonstrate the general misunderstanding of the genetic cause of albinism.

- *Laughing at PWA can result in having a baby with albinism yourself*
- *PWA don't die, but disappear, suggesting they have magical powers*
- *PWA are viewed as a curse, a punishment from God*

- *PWA can be viewed as demons or ghosts, not 'real' human beings*
- *They are given derogatory names such as 'pig'*
- *Having sex with a PWA can cure HIV/AIDS and lead to easy wealth*

This appears to affect women more than men, with documented cases of rape of women with albinism.

Key facilitators:

Family acceptance at birth

The support of parents is crucial for a good start in life, but many fathers and, very rarely, mothers abandon children with albinism when they are born, which means that these children start their lives with additional challenges. Acceptance by someone in the family, be it the mother, grandmother or other carer/guardian is critical. A male supporter provides security for the new baby in both safety and economic terms. Given the widespread lack of understanding of the inherited nature of the condition, rejection is sometimes by the wider extended family; acceptance is greater in families where there have been prior cases of albinism in the family.

Role of government and non-governmental organisations (NGOs) in supporting families

The important role fulfilled by SNUPA (Uganda) and Standing Voice (Tanzania) in both advocacy and health services (Sun Protection and Visual Impairment programmes) was mentioned by participants.

Many participants felt the government could do more to support PWA, particularly financially, with help with start up capital to develop small businesses to support their families. They felt the reliance on charities and NGOs was not sustainable and the government should take over responsibility for delivery of health and other services essential to their survival and well being.

The role of faith and belief

For many PWA and their families, God is seen as a major source of support and comfort, worthy of gratitude for helping PWA through difficulties in their lives. Being born with albinism is seen as part of God's plan and will.

PWA made in God's image

For some, especially religious leaders, the idea that people are made in God's image is used to show that PWA are equal to other people.

At school: overcoming security, social and health problems

Barriers to educational inclusion at school include the discrimination, isolation, bullying and problems with teachers, as well as with their visual impairment. Where teachers and friends are supportive, people with albinism are able to succeed in schools.

- Fear of the danger of attack on the journey to/from school; vigilance of peers and all members of the community in identifying potential risks help to make children feel safe

- Support of friends and teachers at school have a huge impact on the school experience of a learner with albinism

Their short sightedness may not be recognised by teachers and peers at school, so they are perceived as 'difficult' as no adjustments have been made to accommodate them in the classroom. Training of teachers on how to manage this vulnerable group of pupils is needed, by being embedded in teacher training manuals from primary level.

Sun protection from birth

The threat of sun exposure, leading to sun-induced skin damage and potentially skin cancer, limits their daily activities including travelling to school and ability to work outdoors.

Participants mentioned various strategies to manage their vulnerability to sun induced skin damage. Some were innovative and practical, as in the case of a mother who had shown a flap of thick hessian fabric to the rear of her son's hat, to provide additional protection to his neck.

Economic status

Working and having a career is an important life stage. For people with albinism this can be complex. A key concern is that they cannot safely work outside because of the dangers of being in direct sunshine. Due to the cycle of deprivation people with albinism face, economic status becomes particularly important. Better economic status can make the lives of people with albinism less difficult in many ways, including making it easier to find a partner.

Community leaders and journalists in Uganda pointed to the role of poverty in the lives of PWA, as do the families themselves in both countries. Difficulties at school and at work can lead to PWA finding themselves in poverty, leading to further hardship. Having a small scale business, a shop or a tailoring business, generates respect and status as well as income. Participants called on the government to provide start up capital for PWA.

Relationships- finding a partner

There is evidence, notably from Tanzania, that people with albinism can form successful relationships, despite barriers. There can be opposition to marrying someone with albinism from the family of the person without albinism, but the (potential) partners of people with albinism show courage and strength of character to overcome this opposition, often at great personal expense. There is also discrimination towards people who associate with people with albinism.

There is a clear disparity across gender, with women more likely to take the burden for albinism than men. It is often the case that mothers are left to care for children with albinism along, which can mean that these children face financial hardships from birth. It also appears to be the case that men with albinism find it easier to marry than women with albinism do.

This gender disparity warrants further investigation to see how women with albinism and mothers of children with albinism can be better supported.

Integration into society; changing attitudes by awareness and education

In Tanzania participants presented a strong sense of improving attitudes towards people with albinism, which is often attributed to successful awareness campaigns and challenging myths about albinism, where understanding albinism and knowing that people with albinism are just like everybody is used to explain a reduction in prejudice. Government and NGO campaigns were praised as the main reason for the improvement in attitudes that are so important for people with albinism.

Outputs

In addition to academic outputs, evidence based resources produced as a result of this project included development of a children's booklet available at <https://pureportal.coventry.ac.uk/en/publications/born-with-albinism-in-africa> explaining key features of albinism, making maximum use of images and minimum use of text. The target audience is young people with albinism, but it will also be useful for their mothers. In addition a series of comic strips using humour and scenarios from the study were developed by a local Tanzanian artist which can be used in multiple platforms to raise community awareness. In the final dissemination event in Tanzania these attracted much attention and comment, including from the guest of honour on Ukerewe, the District Commissioner. These have been produced in both English and Swahili and can be accessed at <https://vimeo.com/user75356817>