

Albinism in east and southern Africa

Knowledge based upon a descriptive literature review
of research

This literature review was conducted as part of the applied research “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” lead by Coventry University, in partnership with Advantage Africa and Standing Voice. This work was conducted by Anita Franklin (Reader in Children and Family Research/ Faculty of Health and Life Sciences, Coventry University) and Patricia Lund (Principal Lecturer in Genetics/ Faculty of Health and Life Sciences, Coventry University).



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- The call for projects: selection and funding of applied disability research projects
- The coordination of the Resource Center. Internationally concerned, the Resource Center Applied Research and Disability aims at creating connections and bonds between researchers and field stakeholders¹. It develops and disseminates research in order to promote an inclusive social transformation and to facilitate the full involvement of persons with disabilities.

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¹ **Field stakeholders**

Persons with disabilities, their families, and their representative organisations. Any Human Rights organisation working with persons with disabilities. Service providers and other organisations working with Persons with disabilities. Service providers and other organisations working in mainstream that are required to meet the needs of persons with disabilities such as architects, teachers, companies, industries etc. Researchers and research institutes. Local, national and international decision makers.

The present document was conducted as part of the applied research “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” led by Coventry University, in partnership with Advantage Africa and Standing Voice. It was funded by FIRAH’s (International Foundation of Applied Research on Disabilities) call for projects in 2014. The review was conducted by: Anita Franklin (Reader in Children and Family Research/ Faculty of Health and Life Sciences, Coventry University) and Patricia Lund (Principal Lecturer in Genetics/ Faculty of Health and Life Sciences, Coventry University).

The goal of this literature review is to report on existing knowledge about applied research on the theme of Albinism in east and southern Africa. It resulted in the selection of relevant research which were each categorised using a set of predetermined criteria. Of these research, 10 were selected as being particularly relevant or interesting because of their potential for being applied with practical effect, especially with persons with disabilities and their own organisations

What FIRAH means by the very general terms of applied research is:

- First, it is proper research based on precision and methodologies which allow the implementation of a scientific approach involving teams of one or more researchers or academics whose research is one of the statutory missions.
- Applied research differs from basic research. Its ultimate purpose is to increase independence and social participation of people with disabilities. It is not only aimed at producing theoretical knowledge but also tackling practical issues related to the needs and concerns of people with disabilities and their families. The collaboration between these people, professionals and researchers is a fundamental element to the achievement of this type of research.
- This type of research is designed to produce directly applicable results. In addition to usual publishing (scientific articles, research reports) applied research is also designed to produce other publications called “means of application²” which can take various forms: development of good practices, methodological guides, training tools, and are destined to different field stakeholders (people with disabilities, professionals, policies makers).

This work does not intent to be comprehensive but to identify the results and knowledge generated by research that could be useful for field stakeholders in order to improve the quality of life and social participation for people with disabilities.

Each title in the annotated bibliography contains a link with free or paying access to the work in question.

Each reading note contains a link to the relevant research documentary note on the Resource Centre website.

² **Means of application**

Shaping of the findings and knowledge gained from applied research into products, services and contents to meet the expectations and needs of people with disabilities. These application supports are adjusted to be used by field stakeholders.

This document can be freely disseminated provided the source, author and relevant organisations are acknowledged.



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Table of contents

Editorial	8
Summary	9
Introduction.....	9
Frequency of albinism in Africa	9
Health issues: Skin cancer	10
Health issues: Eye care	11
Abuses of people with albinism	11
Attacks in Tanzania.....	12
Nature of the attacks and their impact	12
Government response to the attacks in Tanzania	13
International response to the attacks	15
Raising awareness	15
Critique of media representation.....	17
Research on the lived experiences of people with albinism.....	17
Access to rights.....	18
Access to protection of life.....	19
Access to health protection.....	20
Access to information.....	20
Access to education.....	21
Access to employment	22
Marriage and relationships	22
Empowerment of people with albinism and their families.....	23
Conclusion	23
Reading notes.....	25
Reading note 1. The myths surrounding people with albinism in South Africa and Zimbabwe	26
Reading note 2. Labeling albinism: language and discourse surrounding people with albinism in Tanzania.....	27
Reading note 3. Media Analysis of Albino Killings in Tanzania: A Social Work and Human Rights Perspective	28
Reading note 4. Advocacy for minorities in Africa: Issues and lessons in advancing the rights of Albinos in Tanzania and Osus in Nigeria.....	29

Reading note 5. A sociological study of children with albinism at a special school in the Limpopo province.....	30
Reading note 6. A health intervention programme for children with albinism at a special school in South Africa	31
Reading note 7. Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi	32
Reading note 8. Humanities and Social Science.....	33
Reading note 9. The experience of people with oculocutaneous albinism	34
Reading note 10. Mothers' experiences of genetic counselling in Johannesburg, South Africa	35
Annotated Bibliography	36
Background information on albinism	36
International Policy documents	36
Journalistic and Media Reports and Features	37
Reports from relevant NGOs :	39
Peer Reviewed Publications:	40
a)Health issues affecting children and adults with albinism.....	40
b)Educational issues affecting children with albinism	42
c)Discrimination and Abuses of People with Albinism.....	43
d)Research on the lived experiences of people with albinism.....	44

Editorial

This literature review highlights the significant challenges faced by people with albinism living in Africa. These range from physical danger to life through attacks and murders, to inadequate health and educational resources to meet the specific needs resulting from their visual impairment and susceptibility to skin lesions and cancers. Stigma and discrimination permeate all aspects of their lives and limit social integration. The evidence also points to the difficulties faced by families in trying to protect members with albinism, particularly children, from attacks, whilst maintaining their rights to freedom of movement, family life and choice.

Media and NGO reports have been used to follow the nature and impact of attacks on people with albinism in Tanzania, with some recent evidence that these are declining, although under reporting makes the scale of the problem uncertain. Despite efforts by government and other agencies, concern for their security continues to dominate the lives of those with albinism. Poverty and ignorance are key factors driving the traffic in body parts of those with albinism, mistakenly believed to bring wealth and good fortune.

A lack of understanding of albinism, even among professionals, limits the effectiveness of any support offered to families, and reinforces stereotypical beliefs and misconceptions. The importance of education and raising awareness about albinism at all levels is stressed by many authors, as a way to challenge deeply entrenched mistaken beliefs and myths, and lead to better acceptance.

Although evidence on solutions remains limited, the research highlights specific ways in which the lives of adults and children with albinism could be improved with some authors stressing that any intervention strategies that attempt to address health and/or social issues affecting this group need to be holistic and mindful of the cultural, value and belief systems of the local communities (Lund and Gaigher 2002). NGOs such as Standing Voice and Under the Same Sun in Tanzania, and Advantage Africa in Uganda, have been active in devising programmes for addressing the various needs of families with albinism.

The evidence also examines the importance of empowering people with albinism so that they can lead and/or work in partnership with others to bring about change. Both national groups and international agencies such as the United Nations are becoming directly involved in promoting the human rights of those with albinism in Africa.

Overall, the available literature is limited, with significant gaps in the research evidence base including a paucity of studies which give a voice to adults and children with albinism, and to the families of children with albinism.

Summary

Introduction

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 and misconception, and in some cases violent assault and murder.

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 which causes eyes to move from side to side, photophobia, poor depth perception, strabismus (squint), poor visual acuity and refractive errors. In one study 85% of children with albinism in South Africa had less than 30% vision, even with the best optical correction (Raliavhegwa et al. 2001).

Frequency of albinism in Africa

Both governmental and charitable agencies need realistic and accurate information on the frequency and distribution of people with albinism in the populations they support, to enable them to plan and target health, educational and social welfare resources effectively. At a time of danger, as has been the case for families with albinism in Tanzania since 2008, with the attacks on people with albinism, it becomes imperative to know the number of people who are vulnerable and need protection, particularly in rural areas.

Determining the number of people with albinism in a country is difficult, even though the appearance of those with oculocutaneous albinism is obvious in African populations, given their pale appearance compared with the dark skin, hair and eyes of their peers. The World Health Organisation attempted to obtain data on albinism in Africa, with estimated overall frequencies varying from 1 in 5000 to 1 in 15,000 in different countries (Hong et al. 2006). This is higher than the estimated worldwide frequency of 1 in 20,000 quoted by the US' National Institute of Health (NIH 2016).

Few large scale surveys on albinism have been conducted in African populations. One epidemiological study of 1.6 million schoolchildren in Zimbabwe gave a frequency of 1 in 4182 for the country as a whole, although the distribution was not even, with 73% of the pupils identified attending rural schools (Lund 1996). There were hotspots where the prevalence of albinism was significantly higher, notably in the capital city of Harare with a frequency of 1 in 2661 (Kagore and Lund 1995). In a geographically isolated area of the Zambezi River valley 1 in 1000 people had albinism (Lund et al. 1997). Across the border to the south of Zimbabwe, in northern South Africa, a community based survey of 35 rural villages gave a prevalence of 1 in 2239 among the Venda people. Even in this limited geographical area, the frequency in one clan was significantly higher, at 1 in 832 (Lund et al. 2007).

Estimates in Tanzania have varied widely and wildly, with advocacy groups suggesting there are over 100,000 people with albinism, an unrealistic figure in a total population on the mainland of about 43.6 million, as this would suggest a prevalence of 1 in 436 (Gilgoff 2013; BBC News April 2008).

The Tanzanian National Census of 2012 documented 16,127 people with albinism (8872 male and 7255 female) giving a frequency of 1 in 2652 (The United Republic of Tanzania -National Bureau of Statistics and Office of Chief Government Statistician 2014: Tables 10.1 to 10.4). The distribution of albinism varied, with frequencies ranging from 1 in 2015 in the central Dodoma region (where the capital is located) to 1 in 4586 in the north western Kagera region around Lake Victoria.

Other estimates from Tanzania suggest a higher figure of around 1 in 1400 (Luande, Henschke and Mohammed 1985), but this estimate is based on registered patients with albinism at a Tumour Centre in Dar-es-Salaam and cannot be extrapolated to the country as a whole.

Anecdotal evidence suggest the 2012 Tanzanian census underestimates the number of people with albinism, and statistical studies are being undertaken in Tanzania to analyse these data. Local albinism associations in Africa are developing registers to identify families with albinism and record their contact details, to facilitate better protection and support.

Health issues: Skin cancer

The health needs of those with albinism differ from the general (black) population in Africa. In this group sun exposure results in many types of injury to the skin, ranging from sunburn and blisters, to more permanent damage such as thickening and wrinkling of the skin, and potentially life threatening skin cancers. Lack of recognition and appropriate treatment of pre-malignant stages can lead to aggressive cancers and early deaths. Even for those who manage to access specialist care, the cost is often prohibitive. The need for government and other agencies to intervene to address these needs have been highlighted, to ensure this group receive appropriate health care (Lekalakala et al. 2015).

A study in a tumour clinic in Tanzania where 350 people with albinism were monitored over two years reveals the scale of skin problems for those with albinism and highlights the high risk of developing life-limiting skin cancers in this group due to a lack of protective melanin (Luande, Henschke and Mohammed 1985).

In this equatorial region, with high levels of ultraviolet radiation year round, chronic skin damage was noted by the first year of age, with pre-cancerous lesions by the age of 20. Half (54%) of those in the 11 to 20 age group had clinical cancer with the earliest documented case of cancer in a nine year old. Most of the skin cancers were found in the head and neck region, areas not usually covered by clothing. One of the oldest in the group showed no clinical skin cancer at an age of 60; he had received community support which meant he had not worked out in the sun all his life. Most of the other adults had outdoor occupations, with only 12 working indoors and able to limit their solar exposure.

A retrospective study of 64 cases of skin cancer in patients with albinism at a large referral hospital in the Lake Region of Tanzania found that most (54; 84%) of the patients were below 40 years of age, with 5 (8%) in the 11 to 20 age group (Mabula et al. 2012). Most presented late at the hospital with large tumours; reasons for this late presentation included financial constraints, long distances to health facilities, as well as self-medication at home and treatment by traditional healers. The main treatment offered at the hospital was surgery, with limited options for radiotherapy as this centre did not have

these facilities. Despite these challenges over 80% of survivors were healed, with no recurrence at 12-24 month follow up.

Tanzania has trained dermatology specialists able to treat pre-cancerous lesions (solar keratosis) and skin cancers in people with albinism, with active sun protection programmes supported by the charity Standing Voice and others. Local experts have called on the government to allocate sufficient resources and equipment to provide adequate treatment for those with albinism (Kennedy 2013). The charity Advantage Africa (2016) has introduced cryosurgery to remove pre-cancerous lesions from the skin of people with albinism for the first time in Uganda. Their support also covers access to hats, high-factor sun screen, dermatology and other health care services.

Health issues: Eye care

The lack of optometrists and ophthalmologists in countries such as Tanzania, particularly in rural areas, means that the visual impairment associated with albinism is sometimes not recognised and often not addressed. Programmes by local charities and NGOs aim to meet this need.

In March 2016 the Tanzanian government launched a collaborative programme with development partners called Vision for Life to address the specific visual needs of 4,200 children with albinism in six regions of the country, with the aim of enhancing their education opportunities (Matthew 2016). Local optometrists will implement the programme, providing sunglasses to protect the eyes from ultraviolet and corrective lenses to improve their vision, as they are very photosensitive due to the lack of protective melanin pigment in their eyes.

Abuses of people with albinism

There is a misconception that the body parts of people with albinism can bring good luck, success, and easy wealth. This leads to them being targeted for their hair, limbs, bones, genitals, and other body parts, which are used by local practitioners (or witchdoctors) in their rituals and charms. A local Tanzanian reporter offers this explanation: 'Such attacks are due in large part to widespread superstition in East Africa that body parts of people with albinism carry magical powers that witchdoctors claim to harness....' (Saramba Ongiri 2016).

On the other hand, those with albinism are also believed to be a curse and bring bad luck. The first MP with albinism to be appointed in Tanzania, Ms Kway-Geer, described her life as a schoolchild: 'When I was at primary school, people used to laugh at me, tease me - some didn't even like to touch me, saying that if they touched me they would get this colour. People used to abuse me on the road when I took the buses to school. They would run after me - crowds of kids following me - shouting 'zeru, zeru' (a derogatory term for someone with albinism)." (BBC News April 2008).

Bucaro (2010) highlights some of the cultural superstitions in Tanzania whereby the health issues faced by people with albinism are seen to be a result of a curse or as 'omens of disaster'. Mothers of children with albinism can be blamed for their child's condition and accused of infidelity. Thus many children with albinism are raised without paternal support, creating financial difficulties and an inability to be able to afford health care or education for their child (Bucaro, 2010). Other authors have explored the articulation in society that albinism is 'God's will' (Baker et al. 2010). Brocco (2015) highlights the negative labels and terminology used to describe and define people with albinism in Africa and is one of only a few studies which explore the negative effects of this directly with people with albinism.

Pooe-Monyemore et al. (2012) observed that, despite the efforts of government departments in South Africa to raise awareness and train health professionals, there was still a lack of understanding of albinism amongst those who should be supporting people with albinism, and within the wider community – often leading to negative attitudes and social isolation.

Attacks in Tanzania

Attacks on people with albinism in Tanzania came to international attention as a result of advocacy by agencies such as the Canadian charity Under the Same Sun, reports by the International Red Cross (2009) and investigative journalism by the BBC correspondent in Dar es Salaam, Vicky Ntetema (2004) and others (BBC News July 2008). Ntetema's life was threatened after her exposure of the use of body parts of those with albinism by witchdoctors, and she was forced to go into hiding in 2008.

Following a government campaign, reports of attacks on people with albinism diminished, with none in 2011. In 2015 the United Nations expressed concern that an upsurge in killings that year could be linked to the upcoming elections in Tanzania, 'as political campaigners may be turning to influential sorcerers to improve their odds' as reported by The Citizen Reporter (March 2015). An increase in the number of killings and mutilations, in both Tanzania and neighbouring countries such as Malawi and Burundi, in the approach to the October 2015 elections in Tanzania was of international concern, with reports suggesting that politicians were sourcing body parts of those with albinism in an attempt to improve their performance at the polls. The Deputy Minister for Home Affairs was quoted as saying in parliament that 'I want to assure my fellow politicians that there won't be any parliamentary seat that will be won as a result of using albino body parts' (Lugongo 2015).

Under the Same Sun document all attacks of people with albinism in Tanzania, including reports from families and police. In April 2016 they had recorded a total of 160 abuses, including 76 killings, 65 who had survived but were traumatized and often mutilated, one abduction, 16 grave robberies and two failed attempts to rob a grave. There have been no reports since February 17, 2015, when a one year old baby was killed (Under the Same Sun 2016). Under the Same Sun highlight that numbers are, however, likely to be under-estimates due to the rural locations, corrupt police investigations and a lack of will to investigate attacks, and the deeply entrenched views in the use of witchcraft. In the case of children, their murders often take place shortly after birth or at the hands of family members, and may remain unrecorded.

Nature of the attacks and their impact

An editorial in the local press commented that the killings of people with albinism 'shame the nation' (Editor 2016) and journalists have been active in documenting and reporting cases of abuses of families with albinism. These accounts reveal the impact of these attacks on the whole family, and the importance of community vigilance and support in helping to stop them, as illustrated in an interview by Salim Kikeke (2014), who visited the island community of Ukerewe for BBC Africa:

'A local fisherman describes how attackers tried to kidnap his young son when he was three months old. They waited until he was out fishing, but his mother escaped by jumping out of the window with her son in her arms, leaving her other children behind. They were unharmed but the attackers followed her and only retreated when she screamed for help from neighbours'.

People with albinism in the Lake region have reported repeated attempts on their lives, with one man fleeing his home island of Ukerewe after a village elder tried to kill him for his hair. Even on the mainland he was not safe, with further attempts (Kikeke 2014).

The constant fear of attack has made people with albinism fearful of undertaking even ordinary every day activities. For example, a villager who had lost a hand in an earlier attack was reported missing in March 2016 after travelling to a neighbouring village to sell vegetables. A relative described the family's pain at not knowing whether he was alive or not, and called for a 'concerted war against perpetrators of the barbarism' (Mesomanya 2016).

Investigative Western journalists have gone undercover to obtain first hand stories from local contract killers of people with albinism, who are sent out by witchdoctors to obtain the body parts of people with albinism. Mail online reporters posed as owners of a diamond mine to meet a witchdoctor where they were offered an arm of someone with albinism which the seller claimed would 'draw the diamonds out of the rocks' when deposited in the mine (Obert 2015).

According to a local police source suspects they apprehended after the killing of a one year old child in the Lake Zone admitted that they had used 'potions' from witchdoctors when engaged in mining activities in the region (Masinde 2015). In this case the child was found with arms and mutilated and other siblings were given police protection or went to stay with relatives in other villages. The child's father was one of the suspects and the mother was seriously injured when she fought in vain to protect her child (The Citizen Reporter February 2015). In other cases a man died from stab wounds sustained while trying to protect his wife with albinism from assailants who chopped off her arm (Kakwesi 2014) and a young mother was severely injured fighting off a gang who struck at 2 am, saving the life of her 6 year old son with albinism, although he lost a palm to his attackers (Mwangoka 2015).

The cross border nature of the trade was illustrated by a case involving a Kenyan man who lured a friend with albinism across the border into Tanzania with the promise of a job, whereas in reality he was planning to sell him to a witchdoctor he had contacted on a previous visit (Lumanyika 2010).

Government response to the attacks in Tanzania

The Tanzanian government has taken a number of steps to address the attacks against those with albinism, including working with charities to strengthen centres attached to schools where children with albinism could go for protection and education. Although they have promised action to protect families with albinism and bring those responsible for the killings and abductions to justice it continues to be difficult to obtain evidence to secure convictions. Attempts by the police to investigate cases and bring perpetrators to justice are complicated by a number of features of these attacks. They often take place at night in areas where there is no electricity, hindering identification of the culprits (Kikeke 2014). Relatives sometimes collude in the attacks, making it problematic to gather evidence to secure a conviction (Mkama 2016). In rural areas it was often difficult for police to follow up cases and they appeal for help from the public; in one incident they offered a substantial monetary reward for information that would lead to the safe recovery of a young girl with albinism kidnapped by armed men accompanied by a traditional healer (Mhando 2014). In 2016 a police task force was set up to collect intelligence in areas where the attacks were widespread in a bid to prevent these incidents. At

the same time the continuing need for support from community policing was stressed (Reporters in Dodoma 2016).

Following media reports of the attacks in 2008 President Kikwete condemned the use of body parts of people with albinism in rituals and as good luck charms, and ordered a crackdown on witchdoctors who use these (BBC News April 2008). He was quoted as saying that the problem was 'based more on disgraceful witchcraft beliefs than discrimination or violation of human rights' (Tanzania Daily News 2013). As part of this drive he appointed a woman with albinism as a member of parliament, Al-Shymaa Kway-Geer, who expressed her determination to fight discrimination against people with albinism (BBC News April 2008).

In 2013 the Prime Minister officiated at a parliamentary seminar, convened with the support of the United Nations Development Programme and the parliament office, on the challenges faced by people with albinism in Tanzania. The Premier attributed the atrocities to lack of awareness and education. He was caring for five children with albinism and had first-hand knowledge of the skin cancers they faced, one of the children having died while undergoing treatment (Robi 2013).

In an attempt to halt this trade in body parts two witchdoctors were arrested in May 2014 for killing a woman with albinism, removing one leg and several of her fingers (BBC News May 2014). This failed to stop the attacks, and the government announced a ban on all witchdoctors in January 2015. Up to that date there had been only ten murder convictions following 70 killings of people with albinism and the Home Affairs Minister acknowledged that training of police was needed to ensure appropriate evidence was obtained (BBC News January 2015; Smith 2015).

Attacks against people with albinism continued to be reported, often targeting vulnerable youngsters with albinism, as in the 2015 case of a one year old boy in northern Tanzania who was mutilated, with all his limbs removed (BBC News February 2015). In March 2015 four men were convicted of murdering a woman with albinism and sentenced to death; the convicts included her husband and a neighbour (Buchanan 2015). In one region of Tanzania more than 20 witchdoctors were arrested on suspicion of having been involved in the deaths of people with albinism (Musa 2015).

In February 2016 the Deputy Minister for Home Affairs reported that the police had arrested 133 suspects in connection with attacks on people with albinism in Tanzania, with 19 condemned to death for killings although none have yet been executed due to the lengthy bureaucratic process necessary before implementation of the sentence (Saramba Ongiri 2016). This led to political pressure to speed up the process and carry out the hangings (The Citizen 2015).

The newly appointed President Magufuli has demonstrated his support of people with albinism by appointing Dr Possi, a human rights lawyer with albinism, as a deputy minister in the Prime Minister's office with responsibility for People with Disability (Makoye 2015). Possi has been active in advocating for the rights of all those with disabilities, including calling on the media not to use discriminatory words such as 'albino' (Mwema, 2016).

International response to the attacks

African countries have lobbied the international community to advocate for the human rights of those with albinism, such as the joint proposal by Tanzania and Malawi to the United Nations (UN), calling for a combined effort by member states to ensure the security of people with albinism and address the challenges of lack of appropriate employment, health and education rights for this group (Daily News October 2015 and Daily News November 2015).

The discrimination experienced by those with albinism has been highlighted by the Office of the High Commissioner of the United Nations Human Rights with a dedicated [website](#) entitled 'People with Albinism: not ghost but human beings'. Here the misunderstandings prejudice and stigma experiences by those with albinism worldwide are described, with the consequence that 'Albinism is still profoundly misunderstood, socially and medically' (United Nations Human Rights n. d.). On 13 June 2013 a UN resolution promoting and protecting the human rights (civil, political, economic and cultural) was adopted and 13 June designated as International Albinism Awareness Day.

In April 2016 Amnesty International called for Malawi, a country bordering Tanzania, to take action to protect people with albinism, expressing its concerns about the nature of the police investigations and the seemingly light sentences given to convicted perpetrators of albinism-related crimes, given their serious nature. They report a vigilante backlash where local people respond to these injustices in their own way, taking the law into their own hands. In one incident in March 2016 a mob burned to death men who were allegedly found with the bones of someone with albinism (Amnesty International UK 2014).

Alum, Gomez and Ruiz (2009) note that laws protecting people with albinism do exist but need to be effectively implemented. Other authors argue that international responses are identified as being limited to little more than political rhetoric, with only the media and NGOs seen to have had any success in raising awareness and advocacy work (Burke, Kaijage and John-Langba 2014).

Raising awareness

The importance of educating people about albinism as part of the fight against discrimination is widely recognised. President Magufuli of Tanzania has commented on the mistaken beliefs and myths, influenced by superstition that put the security and lives of people with albinism at constant risk (Mkama 2016). The executive director of the Salif Keita Global Foundation in Mali suggests a possible explanation for the killings of people with albinism, that they are believed by many to be 'walking ghosts' rather than real people, that they do not 'really die, so they cannot really be killed. That's the justification for their murders'. As a result, these killings are not perceived as homicide by some (The Citizen January 2015).

Local associations and international organisations are actively working to provide accurate information about albinism to challenge misconceptions and change perceptions about people with albinism, although President Magufuli thinks it will take years to change the mindsets of Tanzanians about albinism (Mkama 2016). Igwe (2015), a Nigerian activist, argues that traditional healers and ritualists could be invaluable allies in a government drive to enlighten and educate the public around albinism, as they understand the 'absurd and irrational nature' which is at the basis of these erroneous beliefs in the power of their body parts to bring wealth and good fortune. In his view 'the government should

focus on getting Tanzanians to understand that this belief has no basis in reason or reality; it is misconception based on fear and ignorance’.

A lawyer/journalist has called for more action from both government and faith based organisations, stressing that the killings of people with albinism was a direct violation of the right to life as enshrined in the Tanzanian constitution (Jingi 2015).

In January 2016 the head of police in Dar es Salaam, affirmed the police’s commitment to the security of those with albinism, supporting the launch of a campaign of stickers to be widely disseminated in the capital to raising awareness of albinism and counter the attacks on people (Lwangili 2016).

Members of the Tanzania Albinism Society (TAS) have also been active advocates and are committed to developing a register of all people with albinism in the country. They recently called for intervention by both the Tanzanian and the East African Community’s parliament to seek a permanent solution to the crisis (Mesomapyra 2016). Other local groups in Tanzania such as Imetosha, started by a journalist with albinism, have been set up with the aim of changing people’s perspectives on albinism. He has used social media to gather supporters, organised charity walks, used events such as football matches to call publicly to end the killings, and gathered prominent local figures such as artists and musicians to support his campaign (Gregory 2015).

Under the Same Sun have called for greater understanding of albinism by including this as a topic in the teaching curriculum from nursery school, so that children understand albinism from a young age, resulting in less stigmatisation and greater acceptance of this group as part of the community (Tambwe 2013). They have collated [materials](#) to educate teachers, caregivers and the community at large about albinism in an effort to eliminate stigma and discrimination. Their Educational Service Provision Guide for Children with Skin Disabilities was launched through the Ministry of Education and Vocational Training in 2013, to be sent to education officers and school heads (Saiboko 2013).

Under the Same Sun hosted a Pan African Albinism [Conference](#) in Dar es Salaam in November 2015 (<http://www.underthesamesun.com/conference>) which focussed on empowering those with albinism in Africa to advocate for their human rights, and provide the tools to help prevent attacks. Over 200 participants from 29 African countries attended this event (Mkama 2016).

Other methods have also been used to educate communities. In 2013 a series of radio shows ‘Understanding Albinism’ was broadcasted on community radio stations around the Lake area, including radio dramas and live phone-ins (Tambwe 2013). The Albino Enterprises of Dar es Salaam (AED) produced stickers calling for the killings of people with albinism to stop. These were disseminated widely in the city, to be used on motor vehicles, motorcycles, in offices, buildings, shops, schools and colleges in order for the message to reach a large audience. The director of AED commented on the psychological effect of the killings on families:

‘When people with albinism heard that their fellows are being cut (mutilated), the situation led to psychological death’ (Lwangili 2016).

Musicians with albinism in Africa have used their musical talents in their advocacy efforts. John Chiti (2015) from Zambia wrote a song entitled ‘I can do what you can do’ and a Ugandan group use song

to advocate for the rights of persons with disabilities and express their appreciation to those who have contributed towards the advocacy of their rights (Paul and Peter Ft Hellen 2016). Musicians who do not themselves have albinism have also used their talents to highlight the plight of people with albinism in their countries, such as Malawian songwriter James Kuchilala (2016).

Families have also been vocal in seeking more community education about albinism. In a BBC report the father of a young boy with albinism targeted for his body parts urges the government to do more to educate the island community where he lives about albinism. The article stresses the need for awareness campaigns not to be restricted to urban areas only, but also reach rural communities where those with albinism face the greatest threat. The chair of the albinism society on Ukerewe Island describes the difficulties in reaching remote and scattered villages on the island, relying on radio and television (Kikeke 2014).

Critique of media representation

As illustrated above the violence toward people with albinism has been documented and highlighted in the media with reports of dismemberment and killings in Tanzania and other regions of central and east Africa (reviewed in Cruz-Inigo, Ladizinski and Sethi, 2011). Authors from an anthropological and sociological perspective have in the past critiqued the media for their simplistic view of blaming traditional superstitions for the killings, instead of identifying that contract killers are fulfilling a market demand for body parts which are said to bring wealth and fortune – a direct result of the boom in the mining market, rapid social change and new forms of inequality in wealth and power (Burke et al. 2014; Bryceson et al. 2010). Bundala (2010, quoted in Bucaro 2010) argues that poverty drives the violence towards people with albinism, highlighting how the ‘global economic meltdown has turned thousands of people into believing that only through [this type of activity] they can sustain their livelihood’ (p 133).

Media reports of violence against people with albinism have mostly focused on identifying and punishing the perpetrators, although there are articles focused on awareness raising activities, reporting on the protection of people with albinism, working towards a reform of the law and political activism (Burke et al. 2014). Burke et al.’s content analysis of media reports highlights how some of the strategies aiming to prevent abuse or violence are criticised and debated, highlighting the complexities involved in protecting and promoting competing rights.

The profound effects of the violence are also documented in the media, illustrating how family members are forced to escort their children to school or when out in the community. Others report hiding their children at home, seeking asylum in police stations, moving to safer parts of the country or sending their children away to boarding schools, camps or relations in safer areas (Burke et al. 2014). It is argued that media attention placed on the violence towards people with albinism has also led to a realisation of the need to address other challenges facing this group, including stigma, lack of access to education and inadequate access to health services (Burke et al. 2014).

Research on the lived experiences of people with albinism

Despite widespread reporting in the media and via non-governmental organisations on the negative aspects of living with albinism in Africa, little rigorous research has been undertaken on the psychosocial aspects of living with albinism (Pooe-Monyemore et al. 2012), and on the lived

experiences of people with albinism. In particular, the voices and views of children living with this inherited condition remaining largely unheard. Little has been written from a social work, sociological, rights or disability perspective, leaving a large gap in understanding the issues facing people with albinism and measures which could be taken to better support and protect them.

A small number of studies explore the impact of discrimination on the self-identity and self-esteem of adults with albinism. A qualitative study of 15 adults conducted in South Africa highlighted the negative effects the external environment can have on the self-image of people with albinism, and their sense of belonging at home and in the wider community (Pooe- Monyemore et al. 2012). Previous studies have also identified prejudice and stigma as major challenges faced by most people with albinism (Gaigher, Lund and Makuya 2002, Pooe-Monyemore, 2003; Phatoli, Bila and Ross 2015). Pooe-Monyemore (2003) particularly highlights the concerns adult participants in this study had about the common myth that people with albinism do not die naturally, but instead disappear or vanish.

A sample of children with albinism in Zimbabwe reported problems they encountered around other children avoiding, antagonising and even fearing them (Lund 2001). The social isolation of children with albinism can also be confounded by the barriers they face to being able to play outside with other children, and take part in outdoor activities at school. The development of self-esteem through group and team activities is thus being denied to this group (Lund and Gaigher 2002).

It could be argued that the lack of knowledge around one's own condition and how to access care and support can only compound issues of low self-esteem and negative self-identity. A study by Masanja, Mvena and Kayunze (2015) specifically reports on the situation for 156 people with albinism in Tanzania, their awareness of and attitudes towards albinism and felt levels of predicament as a result of the killing and attacks of people with albinism. Surveys undertaken with this group indicated that a lack of awareness and understanding was unsurprisingly highest amongst those who had little or no education.

Access to rights

There is a growing recognition and acceptance in Africa that people with albinism are disabled people, although on an individual level people may not necessarily accept or adopt such a label. People with albinism were defined as disabled in 2008 by the United Nations and as such have human rights as defined by the United Nations Convention on the Rights of Persons with Disabilities (CRPD) (UN, 2006). This includes a right to life, education, health services, work and freedom of movement. Children with albinism not only have rights as disabled people, but are also afforded rights under the United Nations Convention on the Rights of the Child (CRC) (UN, 1989) which has been ratified by almost all African governments.

Burke et al.'s (2014) examination of the media representation of the killing of people with albinism in Tanzania argues that government responses to such killings, including the increased segregation of children with albinism, has resulted in 'trade-offs' between competing rights, whereby the need to protect children could be seen as potentially causing further harm to victims and families. This illustrates the complexities of the situation, where enacting a right to protection and safety can lead to loss of other freedoms and rights such as education, work, movement or right to family life. The following table illustrates this complexity:

Table 1 Examples of trade-offs between competing rights of children with albinism

Interventions Criticised in media	Criticised in media	Competing rights	
Children restrained (even by force) at home	Child abuse and neglect	Either Right to security	Or Right to education, right to freedom of movement, right to freedom from abuse
Children placed in institutions	Overcrowding and inadequate facilities, child abuse	Right to protection, right to freedom	Right to education from abuse, right to freedom of movement

Taken from Burke et al., 2014, p 130)

Brown (2011) argues that the concept of vulnerability is at odds with a rights framework. For example when applied to children with albinism, the notion of vulnerability can leverage resources and action to promote their protection and ensure their right to social justice. However, it can also be used to justify a form of social control – which has resulted in the placing of children with albinism in secure schools. Burke et al. (2014) argue that while residential care may be a protection crisis intervention, it cannot be seen as a sustainable solution as it can have negative consequences on families and, the authors argue, on the social and emotional development of children. These authors argue that unless interventions are based on a holistic conception of human rights, which sees human rights as indivisible – then children with albinism will remain socially excluded and segregated from their families and communities. Clearly significant challenges remain in protecting and promoting the rights of children and people with albinism. The evidence suggests that a starting point has to be ensuring the identification, conviction and punishment of perpetrators of violence towards this group of people.

Access to protection of life

Alum et al. (2009) note that laws protecting people with albinism do exist but need to be effectively implemented. International responses are criticised for being limited to little more than political rhetoric, with only the media and NGOs seen to have had any limited success in raising awareness and advocacy work (Burke et al. 2014).

Burke et al. (2014) report on the Tanzanian government response to the violence against children with albinism, including a policy of moving children with albinism from their family homes into special schools and camps in order to protect them. They argued that while this form of segregation might have increased the children’s security, they highlight concerns that have been raised about overcrowding, inadequate facilities and support, incidents of child abuse and family members abandoning their children at the schools. The impact of the policy on family life and on the well-being of the children has received little attention.

Access to health protection

Alongside a right to protection of life, children and adults with albinism also have the right to health protection, including access to skin protection and skin health services. As already mentioned, the high risk of developing skin cancer makes it essential that children with albinism are taught about, and are enabled to implement, effective sun protection from an early age. However, in Lund's study in Zimbabwe, only 23% of her sample of 138 children had ever had their skin examined by a health professional and this was often only when they were babies.

In terms of other health needs, less than half in this sample (46%) had been to a hospital or private optician for an eye test and only 27% had prescription glasses, although 5% of these felt that they did not improve their eye sight (2001).

Similarly, Lund and Gaigher (2002) studying a sample of 38 children attending a rural special school for visually impaired children in South Africa, worryingly noted that the 'sun protection' used by the children were often inexpensive aqueous creams with no sun protection, or if they did have some protection it was inadequate. Lund and Taylor (2008) point to the need for protective clothing and avoiding sun exposure as much as is possible for both children and adults with albinism. Lund (2001) reports on the persistent skin and eye problems of children with albinism in her study in Zimbabwe, and highlights the lack of suitable health care facilities and social care support, with many families relying on support from within their families. This lack of protection presents a real danger to these children due to their increased risk of developing skin lesions and cancers, which can be life limiting.

The general lack of access to quality health related care features significantly in the research, especially access to sun protective measures (sun creams with high factor protection, protective hats and clothing), and access to professionals knowledgeable and qualified to support and treat people with albinism (Pooe-Monyemore et al. 2012).

Access to information

Alongside physical protection, all people, including children with albinism have a right to access to information. Studies have shown, however, that knowledge about their condition is low and patchy, with many misconceptions, again pointing to potential short and long term health risks (Braathen and Ingstad 2006). Lund (2001) identified that over half of the pupils in her sample in Zimbabwe did not know why their skin was pale – common misconceptions being that they thought they had the top (black) layer of skin missing or that it was a result of witchcraft. Lund (2001) reflects how well informed teachers can be an important, effective route for dissemination of information about genetics and health care, especially as they are respected members of the community, whose opinions are valued.

Many studies highlight the lack of information and education on albinism and the role this can play in allowing erroneous beliefs to persist, with calls on government departments to do more to raise awareness of the condition, including information provision for people with albinism and their families on genetics, skin and eye care, and available support groups (Pooe-Monyemore et al. 2012). Two studies examine the potential for genetic counselling in Africa highlight the important role this could have, if delivered sensitively and in culturally appropriate ways. Penn et al. (2010) examined the important role of grandmothers in South African society, exploring the complexity of their beliefs surrounding childhood genetic conditions and the juxtapositioning of some medical knowledge with

beliefs about the causes of genetic conditions being linked to lifestyle and behaviour, as well as social issues, culture, religion and familial factors. The authors argue that these beliefs have implications for genetic counselling practice, as does recognition of the role grandmothers could/should have in the counselling process. Morris et al. (2015) undertook a study of mothers' experiences of genetic counselling in South Africa. Of the 13 mothers who participated, three had children with oculocutaneous albinism. This study showed that although genetic services and genetic conditions were poorly understood, genetic counselling could bring positive benefits to the mothers if delivered appropriately. Positive experiences were said to rest on whether the mothers received adequate information, understood the language used, were given contact numbers and information to take home, were referred for further support, allowed to answer questions and offered emotional support. The qualities of the counsellor were also important, identified as needing to be compassionate, empathetic and respectful. Again this study highlighted the important role of the wider family and community in the lives of the mothers and how this has to be taken into consideration in genetic counselling. Improved genetic knowledge within the community and amongst health professionals was also identified as being significant in supporting the mothers. Both of these studies, however, point to the lack of research in this area in Africa, especially concerning what might be of benefit to families of children with genetic conditions.

Overall, the evidence illustrates that children and adults with albinism want to be better informed. They seek information on what causes albinism, understanding skin and eye problems and knowing what support, including financial assistance, might be available. This highlights the need for widespread information about the genetics and health management of albinism (Lynch, Lund and Massah 2014).

Access to education

There are mixed policies on the education of children with albinism across Africa, meaning children can have very different educational experiences (Lynch, Lund and Massah 2014). In some countries they are educated in specialist schools for visually impaired children whereas in others they attend mainstream schools, often with specialist resource centres attached. However, in some communities children with albinism are not seen as 'worth educating' (Lynch, Lund and Massah 2014). This study also highlights how parents fear sending their child to school as they are concerned for their safety while walking to school, and in the teachers' abilities to keep them safe.

Lund and Gaigher's (2002) study at a special school for children with albinism in rural South Africa provides insight into the education of this group of children, identifying that although the school had access to magnifiers and low vision devices, these were only used in specific lessons such as map reading. The schools aim was to teach the children skills that would enable them to integrate successfully into mainstream schools at secondary level. In Zimbabwe and Zambia children with albinism attend mainstream schools, although inclusion can be challenging. As Miles (2011) identified, some teachers fear teaching a child with albinism, a fear which is driven by superstitious beliefs. Baker et al. (2010) argue that a lack of education and correct information about albinism at a community level inevitably increases the probability of teachers drawing on local myths.

Lund (2001) reports that the main problem encountered by the children in her study in Zimbabwe was the inability to see the blackboard or print in text books because of poor vision. Sixty percent of pupils

in this study felt that no special provision was made for them in the classroom, although some reported that simple measures such as allowing them to sit closer to the blackboard, use large print materials and not share books and have extra time helped them in their education. A further study by Lund and Gaigher (2002) in South Africa identified simple steps that schools can take to better support their pupils with albinism, including providing shutters on the windows, installing covered walkways, having a mobile blackboard that can move around the classroom to minimise glare at different times of the day and allowing pupils to approach the blackboard to read information – measures which can help pupils with poor eyesight and sensitivity to the sunlight.

Access to education and educators with knowledge of how to support children with albinism were identified as gaps in provision in several countries (Dart et al. 2010, Pooe-Monyemore et al. 2012, Lynch, Lund and Massah 2014). Pooe-Monyemore et al. (2012) particularly highlight the role that education and quality teaching can perform in enhancing the self-esteem of children with albinism, promote their personal development and growth, and create a sense of belonging.

In Tanzania, the Minister of Education and Vocational Training reported that there were 2212 children with albinism enrolled in public schools in Tanzania in 2013, leading the Special Seats legislator to accuse the government of not being proactive in encouraging families to send their children to school. Instead they were being hidden at home. She is reported (Said 2013) as saying:

‘These children are considered misfits and dull, not eligible for education. What is the ministry doing to make sure that they learn (in) conducive learning environments that include customised text books, spectacles and other learning aides?’

Lynch, Lund and Massah (2014) identified gender inequalities in the education of children with albinism in Malawi where they undertook a study into support for inclusive education for this group of children. Despite albinism affecting boys and girls equally, they found twice as many boys as girls were attending resources centres offering specialist support for their low vision, indicating a gender bias in accessing this service.

Access to employment

Lund undertook a study of adults with albinism in Zimbabwe and highlighted the difficulties encountered in obtaining employment (Lund, 1998). Similarly, Baker et al. (2010) highlight the prejudices people with albinism face from employers, whilst highlighting that employment is vastly important for this group, both economically and for social acceptance. Kiprono et al’s (2012) study on quality of life for people with albinism in Tanzania recorded that half of his sample of 128 people were unemployed and half of those unemployed felt they had experienced discrimination by employers. Half of those who were employed reported facing many challenges in their work including sun exposure and needs associated with their eye sight; 10% of those employed had also faced discrimination in their work place.

Marriage and relationships

A few studies have highlighted the difficulties some people with albinism face in developing relationships because of the discrimination and stigma attached to the condition (Lund 2001). In particular, the importance of acceptance by the partner’s family and friends is highlighted (Lund 1998).

As an illustration, one study of students in a South African university reported that 6 out of 10 students who did not have albinism stated that they would not date a person with albinism (Phatoli et al. 2015). Kiprono et al.'s (2012) study on quality of life for people with albinism in Tanzania recorded that in their sample of 138 people who were eligible for marriage, over half were single. Of those who were married, half of these reported problems with their partners because of their albinism; similarly half of those who had separated or were divorced said this was because of the colour of their skin.

Empowerment of people with albinism and their families

Pooe-Monyemore et al.'s (2012) qualitative study with 15 participants (aged 18 – 48 years) in South Africa illustrates that people with albinism are keen to be empowered to eradicate myths and misconceptions, fight for their rights and be treated with dignity and equality. This study demonstrates how members of advocacy groups (in this case, Albinism Society of South Africa (ASSA)) valued the role of these support groups, highlighting how access to the services they can provide such as counselling, raising awareness and empowerment enhanced their self-esteem. Employment was perhaps not surprisingly found to correlate to higher levels of self-esteem in this study. People with albinism also identify various stakeholders that should have a role in empowering those with albinism, including government departments, NGOs, the media and the private sector (Pooe-Monyemore et al. 2012). A paper by Fayoyin and Ihebuzor (2014) highlights the range of advocacy tactics used by people with albinism in Tanzania. Using a case study approach, the authors illustrate how advocacy strategies can influence public discourse and societal change. Despite some success, they also highlight the significant barriers to implementing change, particularly around social beliefs, superstitions and misconceptions.

Increasingly, examples of self-advocacy by individuals with albinism as well as by members of their communities are being documented. They are also contributing directly as researchers in academic studies, helping to shape the direction of projects and co-author publications, as shown by the involvement of Bonface Massah, executive director of the advocacy group in Malawi, in an inclusive education study (Lynch, Lund and Massah 2014).

Conclusion

This literature review has highlighted the significant challenges faced by people with albinism living in Africa. Challenges range from actual danger to life through attacks and murders, to inadequate health care protection, with a lack of services to meet their health and educational needs. Stigma and discrimination permeate all aspects of their lives. The research points to the difficulties faced in trying to protect those with albinism from attacks whilst maintaining their rights to freedom of movement, family life and choice.

Although evidence on solutions remains limited, the research does highlight specific ways in which the lives of adults and children with albinism could be improved, with some authors stressing how any intervention strategies that attempt to address health and/or social issues affecting this group need to be holistic and mindful of the cultural, value and belief systems of the local community (Lund and Gaigher 2002). The evidence also examines the importance of empowering people with albinism so that they can lead and/or work in partnership with others locally, regionally and at an international level, to bring about change.

Overall, the available literature is limited, with significant gaps in the research evidence base including a paucity of studies which give a voice to adults and children with albinism, and to their families.

Reading notes

Ten reading notes were selected with attention to the following Resource Centre criteria:

- Criteria 1: Link between the research results and a concrete application of the principles of the UN Convention.
- Criteria 2: Collaboration researcher / those active in the field.
- Criteria 3: Research leading to applied or applicable results, for the improvement of quality of life of persons with disabilities.
- Criteria 4: Research methodology (i.e. peer-reviewed).

Each reading note contains a link to the relevant research documentary note on the Resource Centre website.

Reading note 1. The myths surrounding people with albinism in South Africa and Zimbabwe

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Social Protection, Albinism, Africa

Author's note

The myths associated with albinism in South Africa and Zimbabwe has a profound influence on the lives of people with the condition, from the moment of their birth until their death. The beliefs and superstitions surrounding the condition affect family life and interfere with access to education, employment and marriage. Drawing on a common interest in albinism, specialist research interests, and recent multi-disciplinary studies and research carried out in South Africa and Zimbabwe, we examine these myths and trace their impact on the lives of people with albinism. We trace the actuality of living with the condition in parts of present-day southern Africa, as reported in the first-hand accounts of people with albinism. We compare attitudes to albinism in different cultures and groups, and suggest ways in which the myths that have surrounded people with albinism for so long, which frequently have very negative connotations, can be challenged by a more scientific and culturally neutral explanation.

Commentary

Although not an empirical study, the paper provides a useful account of the myths surrounding albinism in two African countries and examines the negative implications the myths have on the lives and families of people with albinism including the impact the myths can have on education, employment, birth and death.

Reading note 2. Labeling albinism: language and discourse surrounding people with albinism in Tanzania

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Equality and Non-Discrimination, Albinism, Africa

Author's note

This article is based on a qualitative study that set out to analyse the labels and terms attached to 28 people affected by albinism in villages in Kilolo district, Tanzania. Even though national and international attention to killings of people with albinism has attempted to improve general knowledge of albinism and reduce discrimination, most of the community members within the study had little knowledge of the (bio)medical explanations for albinism and tended to marginalize people with albinism. Framed within a wider moral discourse on illness, disability and socially appropriate behaviour, albinism is mostly considered to be God's will or the consequence of past misdeeds within the family, and many of the existing labels for people with albinism express such ideas.

Commentary

The paper reports on an ethnographic study which examines the language used to describe people with albinism. The paper draws upon disability theories examine stigma and acceptance and provides one of few papers to include the voices of people with albinism framed through a disability lens.

Reading note 3. Media Analysis of Albino Killings in Tanzania: A Social Work and Human Rights Perspective

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Equality and Non-Discrimination, Albinism, Africa

Author's note

Murders of people with albinism are a recently emerging human rights issue in Africa, particularly Tanzania. Thus far, public debates about albino killings in Tanzania and other African countries have been dominated by media reports rather than academic writing. This paper presents the findings of a content analysis of Swahili and English Tanzanian media reports published between 2008 and 2011 on albinism and albino murders in Tanzania, and the diverse activities that have unfolded in response to these attacks. Using a human rights framework, the article explores these responses from a social work perspective. It finds that interventions are often framed with reference to African conceptions of humanness. These conceptions are found to be compatible with notions of human rights as relational, in which the various rights and responsibilities of different members of society are seen as interconnected. In practice however, some interventions have resulted in trade-offs between competing rights, causing further harm to victims and their families. To become sustainable therefore, interventions should aim to support all the human rights necessary for the well-being of Africans with albinism, their families and communities. Further research to this effect is recommended.

Commentary

This paper uniquely combines a content analysis of media reports and scrutinises this through a human rights social work frame. The implications of this are examined in terms of what social work interventions are required to support people with albinism.

Reading note 4. Advocacy for minorities in Africa: Issues and lessons in advancing the rights of Albinos in Tanzania and Osus in Nigeria

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Equality and Non-Discrimination, Albinism, Africa

Author's note

Based on its instrumental role, advocacy is recognised as a strategy for influencing policies, programmes, strategies and social practices in development programming. This is why several advocacy campaigns are organised to influence key individuals or institutions in order to effect changes in instruments of social and political governance. However, questions have been raised on its effectiveness in ensuring continual public attention to minority populations and for achieving enduring social change for peripheral issues outside of the mainstream of policy and social discourse. Using a case study methodology, the study identifies a host of direct and indirect advocacy tactics implemented to influence public discourse and broader social change towards two minority groups; Albinos in Tanzania and Osus in Nigeria. The study demonstrates that the utilization of multiple advocacy techniques contributed to influencing public opinion and symbolic actions of specific decision makers in the two countries. Nevertheless, both minority groups are confronted with a combination of deep-seated social beliefs, superstitions and public misconceptions which fuel the violation of their rights. The paper argues that sustainable promotion of their rights would require a coordinated social change response, not just episodic actions and sporadic outcries to incidence of their rights violation.

Commentary

The paper provides insight into the mechanisms adopted by those advocating the rights of people with albinism with Tanzania. Although the paper is limited to one case study, it provides description of advocacy methods utilised and highlights their outcomes, including a critique of what needs to change in order to achieve improved lives for people with albinism.

Reading note 5. A sociological study of children with albinism at a special school in the Limpopo province

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Education, Albinism, Africa

Author's note

This article maintains that it is the social context, as much as, and sometimes more than the physical condition, that largely structures and limits the lives of people with albinism. It deals with albinism from a sociological, rather than a medical perspective. Viewed as such the problems experiencing by affected people stem primarily not from their physical differences but from the way others respond to those differences and from the social and physical environments they have to cope with. The article is based on a study of 32 children with albinism from a special school in the Limpopo province. Educational, health and social problems, attitudes and perceptions about albinism were tested by way of structured interviews. The data reveal an acute lack of information about the causes and consequences of albinism. It projects it as a condition still deeply immersed in myths and superstition resulting in the stigmatising and rejection of affected people. It also discloses a physical environment which is preventing rather than supporting people with albinism from reaching their potential. It calls for a reorientation in dealing with albinism -away from just medical intervention to treating it as a social construct requiring a holistic approach.

Commentary

This empirical study is one of the few that gives a voice to children with albinism. Drawing on sociological theories it examines educational, health and social problems, attitudes and perceptions about albinism from the perspectives of the children. The study makes specific recommendations for addressing both the physical and social/psychological wellbeing of children with albinism.

Reading note 6. A health intervention programme for children with albinism at a special school in South Africa

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Access to health service, Albinism, Africa

Author's note

The genetic condition albinism has a high frequency among the Sotho people of northern South Africa. Affected children have pale hair, eyes and skin—a dramatic contrast to the normal dark pigmentation. Their visual performance is poor and many attend special schools for the visually impaired. Children with albinism experience problems that are, on the one hand, physiological, and, on the other, social-psychological and educational in nature. In this self-report study 38 children at a rural special school described their eye and skin problems, a direct result of their lack of pigmentation, as well as strategies they adopted to manage their condition. A further section of the study deals with the social adaptation difficulties experienced by these children. The questionnaire tested for local belief systems about albinism and how these impact on the socialization of children with albinism. The intervention strategy proposed in this study is based on the assumption that any attempt to address both the health and social problems should be of a holistic, interactionist nature, and be based on the values and belief systems of the local community. In addressing the physical problems, the proposed intervention programme focuses on sensible sun protection habits from a young age and the active participation of the children. To alleviate the social problems a team (interactionist) approach including children, teachers, parents, health officials and the wider community is recommended.

Commentary

This study reports the perspectives and activities of children with albinism attending a special school highlighting their interactions and sun protection habits. The study contributes evidence on inappropriate sun protection management and the effects this has on the children. It also sheds light on their understanding and perceptions of albinism and makes specific recommendation on how life could be improved for children with albinism in school.

Reading note 7. Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Education, Albinism, Africa

Author's note

Oculocutaneous albinism is an inherited condition with significant health and social impact on the lives of those affected throughout sub-Saharan, including in Malawi. Myths and superstitions surrounding the condition lead to stigmatization, rejection and misconceptions. In a participatory study, consultations with educational professionals, children with albinism and their families documented the barriers to full educational access and revealed low-cost strategies that could be implemented in mainstream schools, to minimize the effect of the visual impairment associated with albinism. These were captured in two information booklets in English and vernacular, one for children and the other appropriate for teacher training.

Commentary

This is the only study found which examines the educational inclusion of children with albinism. The issues are examined from multiple perspectives, including children with albinism and the paper discusses practical solutions to supporting this group of children in mainstream education.

Reading note 8. Albinism: Awareness, Attitudes and Level of Albinos' Predicament in Sukumaland, Tanzania

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Equality and Non-Discrimination, Albinism, Africa

Author's note

In Tanzania, persons with albinism (PWA), continue to be less valued, rejected, attacked and killed for ritual purposes. This study examined the situation of PWA and their households resulting from killings and attacks on them. Specifically, the study assessed the level of awareness, attitudes towards albinism and PWA and level of predicament felt by members of households with PWA. An albinism understanding test and attitudinal scales (Likert and Semantic differential scales) were used to determine attitudes towards albinism and level of dilemma felt. A linear regression model was used to determine the impacts of various variables on the level of predicament. Knowledge on albinism was found to be moderate. Levels of awareness were significantly associated with respondents' age ($p = 0.004$), sex ($p = 0.017$), education level ($p < 0.0001$), religion ($p < 0.001$) and ethnic group ($p = 0.025$). Four-fifths of the respondents (80%) had negative attitudes towards albinism and PWA. Unfavourable attitude was highly associated with education level and occupation ($p < 0.001$). Level of PWA predicament was higher among household members being significantly impacted positively by level of albinism awareness ($\beta = 0.500$), but negatively impacted by attitude towards albinism ($\beta = -313$) and age ($\beta = -0.191$). Age, education, sex and belief determined level of knowledge on albinism. Education level determined attitudes of respondents. Albinism awareness determined the level of predicament felt. The fight against negative beliefs and attitudes towards albinism requires properly designed albinism awareness creation programme.

Commentary

This paper reports on one of the few studies to adopt a quantitative approach to determine attitudes towards albinism and level of dilemma felt within a sample of 156 people with albinism. An 'albinism understanding test' and attitudinal scales (Likert and Semantic differential scales) were used, and identified low levels of knowledge and poor attitudes towards people with albinism, not surprisingly this was most acute amongs those with little or no education.

Reading note 9. The experience of people with oculocutaneous albinism

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Equality and Non-Discrimination, Albinism, Africa

Author's note

This article reports the experiences of people with oculocutaneous albinism in South Africa. Oculocutaneous albinism is an inherited disorder characterised by the defective production of melanin, with little or no pigmentation in the skin, hair and eyes. This condition is found globally, with a high prevalence in sub-Saharan Africa and in clusters in South America. People with this condition are often stigmatised and discriminated against owing to myths and superstitions held by the public about the condition. To date no studies have explored the psychosocial aspects of oculocutaneous albinism. A qualitative study was conducted in Johannesburg, South Africa during 2007 where a purposive sample of 15 members of the black population with oculocutaneous albinism participated in in-depth individual phenomenological interviews. One central question was posed to facilitate the interviews: Could you please share your experience as a person with albinism? Data from the interviews were analysed using Collaizi's qualitative data analysis method and three main themes emerged: (1) perceptions of the internal environment, for example the self; (2) experiences in the external environment, for example family and community; and (3) the need for self-development and growth based on their experiences. Recommendations are made to enhance the self-concept of and promote a sense of belonging, self-development and growth in people with oculocutaneous albinism.

Commentary

In-depth individual phenomenological interviews with 15 people with oculocutaneous albinism shed light on the discrimination and stigma they faced. However, the study provides positive description of the desire for self-advocacy amongst people with albinism and the important role that advocacy groups can have in their lives. The paper discusses specific strategies which could enhance self-concept, sense of belonging and self-development.

Reading note 10. Mothers' experiences of genetic counselling in Johannesburg, South Africa

Access to the reading note and to complete documents in the documentary database of the Resource Center

Key words

Access to health service, Albinism, Africa

Author's note

Genetic counselling is offered in diverse settings, and patient reactions vary due to differences in personal, family and community beliefs, local healthcare settings, as well as cultural background. Together, these factors influence how individuals experience genetic counselling. This study aimed to describe and document the experiences of thirteen mothers, with children with Down syndrome, oculocutaneous albinism or haemophilia B, who had received genetic counselling at state hospitals in Johannesburg, South Africa. A qualitative research design drawing on principles of Interpretative Phenomenological Analysis was used. Four voice-recorded focus groups were conducted and the resulting data were analysed using thematic content analysis. Five themes were identified in the data: thrown into the unknown; a worthwhile experience; a break in communication; telling the family and the community; and spreading the word. It was seen that genetic counselling cannot be viewed as a singular experience, but rather as one which is influenced by mothers' lived experiences and their interactions with other healthcare services, family and community members. The results from this study showed that genetic services and conditions were poorly understood, that the experience of genetic counselling varied amongst mothers, and on-going patient support is needed particularly when addressing family and community members. Further research is needed to assess what information is valuable to individuals during genetic counselling and how to deliver this information in a contextually appropriate manner. Greater awareness of genetic conditions is also required amongst communities and healthcare professionals. Valuable insight was gained from this study which can be used to improve local training programmes and genetic counselling services in Johannesburg, and in South Africa.

Commentary

Although this is a small sample, and of the 13 mothers who participated only three of them had children with oculocutaneous albinism, the study shows that genetic services and genetic conditions were poorly understood. However, it also offers insight into possible positive benefits of genetic counselling for the mothers, if delivered sensitively and culturally appropriately.

Annotated Bibliography

The bibliography contains research references that have been identified for the literature review. These references were selected for their relevance to the Resource Center criteria.

A link to each research is available by clicking on the title (the majority of them are on free access).

Background information on albinism

The following epidemiological papers provide background information concerning prevalence of albinism.

- ❖ Lund, P. M., Maluleke, T. G., Gaigher, I. and Gaigher, M. J. (2007) '[Oculocutaneous albinism in a rural community of South Africa: a population genetic study](#)'. *Annals of Human Biology* 34, 493-497.
- ❖ Lund, P., Puri, N., Durham-Pierre, D., King, R. A., and Brilliant, M. H. (1997) '[Oculocutaneous albinism in an isolated Tonga community in Zimbabwe](#)'. *Journal of Medical Genetics* 34 (9), 733-735.
- ❖ Lund, P. (1996) '[Distribution of oculocutaneous albinism in Zimbabwe](#)'. *Journal of Medical Genetics* 33 (8), 641-644.
- ❖ Hong, E. S., Zeeb, H., and Repacholi, M. H. (2006) '[Albinism in Africa as a public health issue](#)' *BMC Public Health* 6 (1), 212.
- ❖ Kagore, F., and Lund, P. (1995) '[Oculocutaneous albinism among schoolchildren in Harare, Zimbabwe](#)'. *Journal of Medical Genetics* 32 (11), 859-861.
- ❖ Raliavhegwa, M., Oduntan, A. O., Sheni, D. D. D., and Lund, P. M. (2001) 'Visual performance of children with oculocutaneous albinism in South Africa'. *Journal of Medical Genetics* 38 (supplement 1), S35
- ❖ The United Republic of Tanzania – National Bureau of Statistics and Office of Chief Government Statistician (2014) "[Basic Demographic and Socio-Economic Profile, Statistical Tables, Tanzania, Mainland](#)"
- ❖ U.S. National Institute of Health (NIH) (2016) "[Oculocutaneous albinism](#)"
- ❖ Yahalom C., Tzur, V., Blumenfeld, A., Greifner, G., Eli, D., Rosenmann, A., Glanzer, S., and Anteby, I. (2012) '[Refractive profile in oculocutaneous albinism and its correlation with final visual outcome](#)'. *British Journal of Ophthalmology* 96, 537-539.

International Policy documents

The following international policy documents have specific relevance to people with albinism highlighting their rights, and detailing how their human rights are not being protected.

- ❖ United Nations (1989) [‘The United Nations Convention on the Rights of the Child’](#). United Nations, Geneva.
- ❖ United Nations (2006) [Convention on the Rights of People with Disabilities](#). United Nations. New York.
- ❖ United Nations Human Rights (n. d.) [People with albinism face multiple forms of discrimination worldwide](#)
- ❖ United Nations Human Rights (n. d.) [People with albinism: Not ghosts but human beings](#)

Journalistic and Media Reports and Features

The following news features report on the current situation facing people with albinism in Africa. The majority of media accounts focus on identifying, and the punishment of, perpetrators of the violence and abuses of people with albinism. However, a smaller number of articles focus on raising awareness of the issues and political activism.

- ❖ BBC News (2008) [‘Living in fear: Tanzania’s albinos’](#). *BBC News*
- ❖ BBC News (2008) [‘Surprise of Tanzania’s albino MP’](#). *BBC News*
- ❖ BBC News (2014) [‘Tanzanian witch doctors arrested over albino killing’](#). *BBC News*
- ❖ BBC News (2015) [‘Tanzania bans witchdoctors over albino attacks’](#). *BBC News*
- ❖ BBC News (2015) [‘Tanzanian albino boy found mutilated’](#). *BBC News*
- ❖ Bucaro, S. (2010) ‘A black market for magical bones: The current plight of East African Albinos’. *Public Interest Law reporter 2* (15), Article 8
- ❖ Buchanan, E. (2015) [‘Tanzania death penalty for suspects in albino murder to ‘serve as an example’](#). *International Business Times*
- ❖ Bundala, R. (2010) *Email Interview with Robert Bundala* [email] to Bucaro, S. cited in Bucaro, S. (2010) [‘A black market for magical bones: The current plight of East African Albinos’](#). *Public Interest Law reporter 2* (15), Article 8
- ❖ Chiti, J. (2015) [I can do what you can do](#)
- ❖ *Tanzania Daily News* (2015) [‘Tanzania, Malawi tout albino rights advocacy’](#)
- ❖ *Tanzania Daily News* (2016) [‘Albino killers shame this nation a lot’](#)

- ❖ Gilgoff, D. (2013) [‘As Tanzania's Albino Killings Continue, Unanswered Questions Raise Fears’](#). *National Geographic*
- ❖ Gregory, S. (2015) [‘Imetosha: The struggle to end albino killings’](#). *The Citizen*
- ❖ Igwe, L. (2015) [‘Healers can be good allies in campaign to protect albinos against’](#). *The Citizen*
- ❖ Jingi, M. (2015) [‘Govt not doing enough to end albino killings’](#). *The Citizen*
- ❖ Kakwesi, R. (2014) [‘Man dies in defence of wife’](#). *The Citizen*
- ❖ Kennedy, N. (2013) [‘Tanzania: Medics call for government to create environment for albinism treatment’](#). *Tanzania Daily Mail*
- ❖ Kikeke, S. (2014) [‘Tanzania's albino community: 'Killed like animals'.](#) *BBC News*
- ❖ Kuchilala, J. (2016) [James Kuchilala sings on albino killing in Malawi](#)
- ❖ Lugongo, B. (2015) [‘Politicians killing albinos’](#). *The Citizen*
- ❖ Lumanyika, G. (2010) [‘Kenyan who tried to sell albino is jailed for 17 years’](#). *The Citizen*
- ❖ Lwangili, J. (2016) [‘Police pledge greater protection of albinos’](#). *Daily News*
- ❖ Makoye, K. (2015) [‘Tanzania appoints first albino deputy minister’](#). *Made for minds*
- ❖ Masinde, J. (2015) [‘Lake Zone: 5 held in albino child murder’](#). *The Citizen*
- ❖ Matthew, M. (2016) [‘NGOs team up to support people with albinism’](#). *Tanzania Daily News*
- ❖ Mesomapyia, J. (2016) [‘Albino attack victim goes missing’](#). *The Citizen*
- ❖ Mhando, A. (2014) [‘Sh3m for recovery of kidnapped girl’](#). *The Citizen*
- ❖ Mkama, A. (2016) [‘Arduous task of protecting people with albinism’](#). *Tanzania Daily News*
- ❖ Musa, J. (2015) [‘Over 20 witch doctors held in Mbeya Region’](#). *The Citizen*
- ❖ Mwangoka, M. (2015) [‘Albino, 6, loses palm to thugs’](#). *The Citizen*
- ❖ Mwema, I. (2016) [‘Disabled deserve respect –Possi’](#). *Daily News*
- ❖ Ntetema, V. (2004) [‘Tanzanian ‘witch killers’ charged’](#). *BBC News*

- ❖ Ntetema, V. (2008) [‘In hiding for exposing Tanzania witch doctor’](#). *BBC News*
- ❖ Obert, M. (2015) [“His blade was dull. He hacked and hacked. There was a jerk, my arm tore off. That’s when I screamed’: Tanzania’s hunted albinos relive the horror of their limbs being stolen by witchdoctors who buy an arm for £1,000 and a head for ‘double’”](#)
- ❖ Paul and Peter Ft Hellen (2016) [Mutuwe Chance](#)
- ❖ Reporters in Dodoma (2016) [‘Albino killers ‘punished heavily’](#). *Tanzania Daily News*
- ❖ Robi, A. (2013) [‘Society for albinos awaits investigation into killings’](#). *24Tanzania*
- ❖ Saiboko A. (2013) [‘Handbook on handling students with albinism launched’](#). *24 Tanzania*
- ❖ Said, M. (2013) [‘Children with albinism miss out on school’](#). *24 Tanzania*
- ❖ Saramba Ongiri, P. (2016) [‘19 face death penalty over albino killings in Tanzania’](#). *The Citizen*
- ❖ Smith, D. (2015). [‘Tanzania bans witchdoctors in attempt to end albino killings’](#). *The Guardian*
- ❖ Tambwe, M. (2013) [‘NGO touts free medical care for albinos’](#). *24 Tanzania*
- ❖ Tanzania Daily News (2013) [‘Kikwete: Disgraceful albino killings now controlled’](#). *24Tanzania*
- ❖ The Citizen (2015) [‘Body lauds ban, but says more needs to be done’](#)
- ❖ The Citizen (2015) [‘Lowassa wants convicted albino killers hanged’](#)
- ❖ The Citizen Reporter (2015) [‘UN calls for action as body of albino child found’](#)
- ❖ The Citizen Reporter (2015) [‘UN links albino killings to 2015 polls campaigns’](#)

Reports from relevant NGOs :

The following sources have been produced by active NGOs supporting People with Albinism and raising awareness of the abuses and discrimination faced by people with Albinism.

- ❖ Advantage Africa (2016) [Improving the lives of people with albinism](#)
- ❖ Alum, A., Gomez, M. and Ruiz, E. (2009) [‘Hocus Pocus, witchcraft, and murder: The plight of Tanzanian albinos’](#) *Under the Same Sun*
- ❖ Amnesty International UK (2014) [‘Hunted for albinism’](#)

- ❖ International Federation of the Red Cross and Red Crescent Societies (2009) [Through albino eyes. The plight of albino people in Africa's Great Lakes region and a Red Cross response](#)
- ❖ Under the Same Sun (2012) [Reported Attacks of Persons with Albinism](#). Vancouver, Canada
- ❖ Under the Same Sun (n. d.) ["Pan Africa Albinism Conference"](#)

Peer Reviewed Publications:

The following peer-reviewed journal articles have been ordered according to their primary focus: Health, Education, Discrimination and Abuse, and the Lived Experiences of People with Albinism. The majority report on empirical research and in a small minority of cases includes the views and experiences of children or people with albinism. Short descriptions of the studies are included :

a) Health issues affecting children and adults with albinism

- ❖ Lekalakala, P. T., Khammissa, R. A. G., Kramer, B., Ayo-Yusuf, O. A., Lemmer, J., and Feller, L. (2015) ['Oculocutaneous albinism and squamous cell carcinoma of the skin of the head and neck in Sub-Saharan Africa'](#), *Journal of Skin Cancer*

This paper reports on the increased risks of skin cancer in people with albinism in Sub-Saharan Africa. The study argues that prevention or reduction of skin cancer could be achieved through raising awareness of the harmful effects of exposure to sunlight and by making available effective screening programs for early detection of skin lesions in schools and communities, and for early treatment.

- ❖ Lund P., and Taylor, J. (2008) ['Lack of adequate sun protection for children with oculocutaneous albinism in South Africa'](#). *BMC Public Health* 8, 225

This study used community based participatory research to investigate sun protection strategies in 90 pupils with albinism boarding at a special school educating pupils with visual impairment in a rural area of northern South Africa. Hats worn and sunscreen preparations used were examined during semi-structured face to face interviews conducted in small peer groups. The study identified that the children were exposed to high levels of ultraviolet radiation throughout the year and showed skin damage despite wearing protective head gear. The authors call for changes in health policy and health care information.

- ❖ Lund, P. M., and 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

This study reports on the perspectives and activities of children with albinism attending a special school highlighting their interactions and sun protection habits. The study contributes evidence on inappropriate sun protection management and the effects this has on children. It also sheds light on their understanding and perceptions of albinism. This paper highlights that interventions that attempt to address health and social issues need to be holistic and sensitive to the culture, value systems and beliefs of local communities.

❖ Lund, P. M. (2001) '[Health and education of children with albinism in Zimbabwe](#)'. *Health Education Research* 16 (1), 1-7

This paper describes the results of a questionnaire survey of 138 children with albinism living in rural Zimbabwe. Questions explored health, social and educational aspects of children's lives. The children reported persistent skin and eye problems. Children had limited knowledge of their condition and were keen to be educated about albinism. The author calls for widespread information about genetics to be made available, and for improvements in interventions which would help children with albinism being educated in mainstream schools.

❖ Lund, P. (1998) 'Living with albinism: a study of affected adults in Zimbabwe.' *Journal of Social Biology & Human Affairs* 63 (1), 3-10 (paper version only)

This paper reports on a study of 39 adults with albinism highlighting how they managed their condition effectively, despite having limited access to specialist health care facilities or social welfare support. Although many had positive relationships within their family and local community, respondents reported issues gaining and maintaining employment.

❖ Luande, J., Henschke, C. I., and Mohammed, N. (1985) '[The Tanzanian human albino skin. Natural history](#)'. *Cancer* 55 (8), 1823-1828

This study reports the results from the monitoring of 350 people with albinism via a tumour centre. Skin changes were followed for at least 2 years and the study identified that chronic skin damage was evident in all participants by the first year of life. By 20 years of age, the skin of every subject demonstrated malignant change, and prognosis was not good for those who did not receive treatment, usually causing death in the third or fourth decade of life.

❖ Mabula, J. B., Chalya, P. L., Mchembe, M. D., Jaka, H., Giiti, G., Rambau, P., Masalu, N., Kamugisha, E., Roberts, S., and Gilyoma, J. M. (2012) '[Skin cancers among Albinos at a University teaching hospital in Northwestern Tanzania: a retrospective review of 64 cases](#)'. *BCM Dermatology* 12 (5).

This paper reports on a retrospective study of 64 people with albinism with a histopathological diagnosis of skin cancer seen at medical centre during the period: March 2001 to February 2010. The authors highlight how late presentation and failure to complete treatment due to financial difficulties and lack of radiotherapy services at the centre are major challenges in the care of these patients. They call for early preventive measures, early presentation and treatment, and follow-up in order to achieve better outcomes for the population.

❖ Morris, M., Glass, M., Wessels, T., and Kromberg, J.G.R. (2015) '[Mothers' experiences of genetic counselling in Johannesburg, South Africa](#)'. *Journal of Genetic Counseling* 24 (1), 158-168.

This study shows that within a small sample of 13 mothers (including three mothers of children with albinism) they have limited understanding of genetic services and genetic conditions. The paper offers insight into possible positive benefits of genetic counselling for mothers, if delivered in a sensitive and culturally appropriate manner.

❖ Penn, C., Watermeyer, J., MacDonald, C., and Moabelo, C. (2010) '[Grandmothers as gems of genetic wisdom: Exploring South African traditional beliefs about the causes of childhood genetic disorders](#)'. *Journal of Genetic Counseling* 19 (1), 9-2.

This pilot study explored South African traditional beliefs regarding common childhood genetic disorders. The authors report on three focus groups conducted with fifteen grandmothers from different cultural backgrounds. Questions focused on the role of the grandmother, traditional beliefs regarding causes of genetic disorders, explanations of heredity, and prevention and management of genetic disorders. Results indicated a variety of cultural explanations for causes of childhood genetic disorders which were classified into categories related to lifestyle, behavior, social issues, culture, religion, genetic, and familial causes. The paper concludes with a call for genetic counseling practice to include a greater focus on cultural issues.

b) Educational issues affecting children with albinism

❖ Dart, G., Nkanotsang, T., Chizwe, O., and Kowa, L. (2010) '[Albinism in Botswana junior secondary schools - a double case study](#)'. *British Journal of Special Education* 37 (2), 77-86

This study reports on the educational experience of two pupils with albinism in junior secondary schools in Botswana. Case studies were carried out by student teachers on teaching practice. Issues arising from the case studies of the two pupils were combined with the life story of a third student teacher who himself has albinism. The authors conclude by making some recommendations as to how the experience of pupils with albinism might be improved in the light of local conditions and principles of development.

❖ Gaigher, R. J., Lund, P. M., and Makuya, E. (2002) '[A sociological study of children with albinism at a special school in the Limpopo province](#)'. *Curationis* 25 (4), 4-11

This empirical study is one of the few to give a voice to children with albinism. Drawing on sociological theories it examines educational, health and social issues, attitudes and perceptions of albinism from the perspectives of the children. The study makes specific recommendations for addressing both the physical and social/psychological wellbeing of children with albinism.

❖ Miles, S. (2011) '[Exploring understandings of inclusion in schools in Zambia and Tanzania using reflective writing and photography](#)'. *International Journal of Inclusive Education* 15 (10), 1073-1102

This exploratory, small-scale study undertaken in 17 schools in northern Zambia and five schools in Tanzania explored understandings of inclusive education at school and community level in northern Zambia and Tanzania in the light of government efforts to promote Education for All. Reflective writing, photo elicitation and participatory photography were some of the methods used to generate local knowledge about marginalisation from the educational process, although the focus is primarily on the issue of disability as a cause of educational exclusion.

❖ Lynch, P., Lund, P., and Massah, B. (2014) '[Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi](#)'. *International Journal of Educational Development* 39, 226-234.

This study examines the social inclusion of children with albinism. The issues are examined from multiple perspectives, including children with albinism and the paper concludes with discussion about practical solutions to support this group of children in mainstream settings.

c) Discrimination and Abuses of People with Albinism

❖ Baker, C., Lund, P., Nyathi, R., and Taylor, J. (2010) '[The myths surrounding people with albinism in South Africa and Zimbabwe](#)'. *Journal of African Cultural Studies* 22 (2), 169-181

This paper explores the myths surrounding albinism and the effects they have on people with albinism in South Africa and Zimbabwe. Birth, family life, education, employment and marriage are areas of life explored.

❖ Braathen, S. H., and Ingstad, B. (2006) '[Albinism in Malawi: knowledge and beliefs from an African setting](#)'. *Disability & Society* 21 (6), 599-611

This article is based on a qualitative project which examined knowledge, beliefs and behavior 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.

❖ Brocco, G. (2015) '[Labeling albinism: language and discourse surrounding people with albinism in Tanzania](#)'. *Disability & Society* 30 (8), 1143-1157.

This article is based on an ethnographic study which examines the language used to describe people with albinism. Utilising disability theory on stigma and acceptance, the paper is one of the few studies to include the voices of people with albinism framed through a disability lens.

❖ Brown, K. (2011) '[Vulnerability: Handle with Care](#)'. *Ethics and Social Welfare* 5 (3), 313-321.

The author explores in this paper some of the ethical and practical implications of 'vulnerability' as a concept in social welfare and highlights how ideas about vulnerability shape the ways in which we manage and classify people, justify state intervention in citizens' lives, allocate resources in society and define our social obligations. The lack of clarity and limited analysis of the concept of 'vulnerability' in welfare arenas is highlighted as concerning, The author concludes that 'vulnerability' is a concept that should be handled with more care.

❖ Bryceson, D. F., Jonsson, J. B., and Sherrington, R. (2010) '[Miner's magic: artisanal mining, the albino fetish and murder in Tanzania](#)'. *Journal of Modern African Studies* 48 (3), 353 – 382

Following a series of murders of people with albinism in Tanzania's north-west mining frontier, this article interrogates the agency of those involved in the murders.

❖ Burke, J., Kaijage, T. J., and John-Langba, J. (2014) '[Media Analysis of Albino Killings in Tanzania: A Social Work and Human Rights Perspective](#)'. *Ethics and Social Welfare* 8 (2), 117-134.

This paper uniquely combines a content analysis of media reports and scrutinises this through a human rights social work framework. The results are examined in terms of what social work interventions are required to support people with albinism.

❖ Cruz-Inigo, A. E., Ladizinski, B., and Sethi, A. (2011) '[Albinism in Africa: Stigma, slaughter and awareness campaigns](#)', *Dermatologic Clinics* 29 (1), 79-87

This paper provides an overview of the discrimination and abuses of people with albinism in Tanzania and other regions of central and east Africa.

❖ Fayoyin, A., and Ihebuzor, N. (2014) '[Advocacy for minorities in Africa: Issues and lessons in advancing the rights of Albinos in Tanzania and Osus in Nigeria](#)' *Asia Pacific Journal of Research* 1 (17)

This paper provides insight into the mechanisms adopted by those advocating the rights of people with albinism within Tanzania. Although the paper is limited to one case study, it provides useful description of advocacy methods utilised and highlights their outcomes, including a critique of what needs to change in order to achieve improved lives of people with albinism.

❖ Kiprono, S. K., Joseph, L. N., Naafs, B., and Chaula, B. M. (2012) '[Quality of life and people with albinism in Tanzania: More than only a loss of pigment](#)'. *Open Access Scientific Reports* 1, 283.

This study reports on the quality of life of 149 people with albinism in Tanzania.

Dermatology Life Quality Index (DLQI) questionnaires were administered and a semi-structured questionnaire was used to collect data on education, work, relationships and sun protection. Half of the participants were discriminated at school, 52% were still single, with albinism reported as the reason for separation or divorce in 50% of those separated or divorced. Discrimination during employment was reported by nearly half of those who were unemployed.

❖ Masanja, M. M., Mvena, Z. S. K., and Kayunze, K. A. (2015) '[Albinism: Awareness, Attitudes and Level of Albinos](#)' Predicament in Sukumaland, Tanzania'. *Asian Journal of Applied Science and Engineering* 3, 14 – 27

This paper reports on one of the few studies to adopt a quantitative approach to determine attitudes towards albinism and levels of dilemma felt within a sample of 156 people with albinism. An "albinism understanding test" and attitudinal scales were used, and identified low levels of knowledge and poor attitudes towards people with albinism especially amongst those people with little or no education.

❖ Phatoli, R., Bila, N., and Ross, E. (2015) '[Being black in a white skin: beliefs and stereotypes around albinism at a South African University](#)', *African Journal of Disability* 4 (1), Art. #106, 10 pages.

This qualitative study explored the beliefs and practices regarding albinism within a South African university, and the availability of support services. Framed using theories of stigma, discrimination and 'othering'. Interviews were conducted with five students with albinism and 10 students without albinism. Findings confirmed the existence of myths and stereotypes regarding albinism. Students with albinism tended to exclude themselves from the rest of the student community to avoid discrimination and stereotypes around their condition.

d) Research on the lived experiences of people with albinism

❖ Poe-Moneymore, M. B. J., Mavundla, T. R., and Christianson, A. L. (2012) '[The experience of people with oculocutaneous albinism](#)'. *Health SA Gesondheid* 17 (1), Art. # 592, 8 pages

This study reports on in-depth phenomenological interviews with 15 people with oculocutaneous albinism and sheds light on the discrimination and stigma they face. However, the study also provides

positive description of the desire for self-advocacy amongst people with albinism and the important role that advocacy groups can have in their lives. The paper discusses specific strategies which could enhance self-concept, sense of belonging and self-development.

The present document was conducted as part of the applied research “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” led by Coventry University, in partnership with Advantage Africa and Standing Voice. It was funded by FIRA’s (International Foundation of Applied Research on Disabilities) call for projects in 2014. The review was conducted by: Anita Franklin (Reader in Children and Family Research/ Faculty of Health and Life Sciences, Coventry University) and Patricia Lund (Principal Lecturer in Genetics/ Faculty of Health and Life Sciences, Coventry University).

The goal of this literature review is to report on existing knowledge about applied research on the theme of Albinism in east and southern Africa. It resulted in the selection of relevant research which were each categorised using a set of predetermined criteria. Of these research, 10 were selected as being particularly relevant or interesting because of their potential for being applied with practical effect, especially with persons with disabilities and their own organisations