

Witchcraft-related Abuse and Murder of Children with Albinism in Sub-Saharan Africa: A Conceptual Review

Babies born with the inherited condition albinism, resulting in reduced melanin pigment in their hair, skin and eyes, are vulnerable in multiple ways in Africa: as children, as visually impaired, as socially ostracised, isolated and excluded, and as potential victims of witchcraft-related violence targeted for their body parts for use in 'lucky' charms thought to bring good fortune. This conceptual review summarises the scarce research on this topic within an integrated framework of otherness (highlighting the ways in which these children differ from others in their group and how this is perceived by themselves and others), watchfulness (the consequences and impact of this very visible difference on families and communities) and agency (what such children themselves and other people can do to respond to these abuses of human rights). The paucity of information on the lives of children with albinism in Africa limits the development of appropriate interventions to support, empower and, most importantly, protect them at this time of danger in the region. This review proposes a conceptual model to act as a platform for research on which to build and enhance our understanding of the lives of children with albinism in sub-Saharan Africa. © 2019 John Wiley & Sons, Ltd.

KEY PRACTITIONER MESSAGES:

- Mutilation and killing of people with albinism, particularly children, have increased over recent years.
- Very little is known about the physical and psychosocial issues facing children with albinism in the context of threats of assault and attack.
- Children with albinism are seen as 'other', with the violent context making them and their families watchful and vigilant. This threatens their agency and safety.

KEY WORDS: child abuse; witchcraft-related violence and abuse; oculo-cutaneous albinism; conceptual review; sub-Saharan Africa

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'This conceptual review summarises the scarce research on this topic within an integrated framework of otherness..., watchfulness... and agency'

‘There is a lack of research on the psychosocial aspects of albinism’

‘The prevalence of albinism has been estimated to be in the region of one in 2000–5000 throughout sub-Saharan Africa’

Introduction

Violence towards people with albinism has attracted increasing media attention over recent years, with incidents of mutilation and killings in some regions of sub-Saharan Africa reported at unprecedented rates (Under the Same Sun, 2018). Children are particularly vulnerable to attack, but very little is known about the physical and psychosocial issues facing them in the context of threats of assault and attack. There is a pressing need to conduct robust, empirical studies in order to understand the experiences of affected children, families and communities.

Babies born with albinism in sub-Saharan countries, lacking pigment in their hair, skin and eyes, differ strikingly in appearance within populations characterised by dark pigmentation. They may face a society that demonises, marginalises, stigmatises and discriminates against those with albinism, especially in rural areas where myths abound and traditional healers are very powerful (Kromberg, 2018). To date, there is a lack of research on the psychosocial aspects of albinism (Pooe-Monyemore *et al.*, 2012) and, in particular, the voices of children with albinism remain virtually unheard. This conceptual review contributes to emerging understandings of the atrocity of abuse against a vulnerable group of children with albinism.

Background

Understanding albinism

The different types of oculocutaneous albinism (OCA) which affect both skin and eyes result from inherited genetic mutations, causing an insufficiency in melanin production, and affect people worldwide.

Although there have been few detailed epidemiological studies, the prevalence of albinism has been estimated to be in the region of one in 2000–5000 throughout sub-Saharan Africa (Hong *et al.*, 2006; Lund and Roberts, 2018).

The lack of pigmentation of those born with OCA means that they are very sensitive to the damaging effects of the harsh African sun, causing severe sunburn, lesions and skin cancers. Albinism also affects eyesight in numerous ways including involuntary nystagmus (oscillation of the eyes), photophobia (extreme sensitivity to light), depth perception and squint (Yahalom *et al.*, 2012).

Terminology

Within the albinism community, there is continued debate about the use of the term ‘albino’, with many people preferring the term ‘person with albinism’, placing the person before the condition (National Organization for Albinism and Hypopigmentation, 2017). We use this throughout except where we quote directly from other sources. We use the term ‘ritualised violence’ to denote violence that derives from a belief in sorcery.

Methodology

We undertook a conceptual review to synthesise the small body of empirical evidence on the violence and ritual murder perpetrated against children with albinism in sub-Saharan Africa. Our purpose was to draw on extant understandings of the issue from a variety of perspectives, using an integrated theoretical framework. We suggest a rights-based approach as an appropriate theoretical lens through which to explore this issue (Franklin *et al.*, 2018). Acknowledging the limitations of a single theory, we combine this with a social model of disability. Together, these encapsulate the experiences of children with albinism within three main themes that permeate the literature and which we have named as otherness, watchfulness and agency. Illustrative quotations from policy documents, lay reports and anecdotes are used to support the conceptual discussion.

Understanding the context of the attacks

Growing up with albinism in Africa herself, the United Nations (UN) Independent Expert on the Enjoyment of Human Rights by Persons with Albinism described:

‘Being hypervisible in a context where the majority did not understand albinism but believed in negative superstitions about it caused great anxiety in my mind. ...never in my deepest fears did I imagine that things would become worse. That a near pan-African scale of violence would be meted out to persons with albinism.’ (Ikponwosa Ero cited in International Bar Association, 2017, p. 7)

Attacks on children range from forcibly shaving off hair, to the mutilation of fingers or limbs, and to murder, with all body parts taken for sale. Reports often include descriptions of perpetrators seeking to obtain body parts for use as ‘good luck’ charms (Cruz-Inigo *et al.*, 2011) arising from a false belief that they will enhance wealth or physical potency (UN Human Rights Council, 2017). Under the Same Sun (UTSS), a non-governmental organisation (NGO) working to change attitudes about albinism, documents all reported serious attacks of people with albinism in Africa, including reports from families and the police. The March 2018 report documented 204 reported killings and 354 attacks (total 558) in 29 African countries in the last ten years (UTSS, 2018). Of those who managed to survive the attacks, most were traumatised and often mutilated. Abductions and grave robberies are commonplace.

These numbers seem small in the context of the overall violence and abuse in the region, but are likely to be hugely underestimated due to rural locations, deeply entrenched views in the use of witchcraft, the secret nature of witchcraft rituals, fear of reporting, corrupt police investigations and a lack of will to investigate attacks, and limited capacity to monitor violations (UN Human Rights Council, 2017; UTSS, 2012).

Verbal abuse (name-calling) and other examples of exclusion from communal events are a regular occurrence for people with albinism, particularly from strangers who do not know them. There are no reliable data on the frequency of different types of violence; events such as cutting children's hair are not likely to be reported officially and have been recorded

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as personal testimonials to NGOs and researchers. More serious crimes such as killings and mutilations are more likely to be recorded and reported in the media. It is therefore not possible to evaluate the relative frequency of these events, but it is clear that there is a constant sense of fear and vigilance among families with albinism.

In the case of children, their murders often take place shortly after birth or at the hands of family members (International Bar Association, 2017). Some of the accounts from the UTSS (2012) report include:

- Twenty-eight-year-old Mariamu who was betrayed by a neighbour and lost both her arms and her unborn child in an attack.
- Baby Yohana who was taken as attackers slashed his mother's face; his dismembered body was found two days later.
- Pendo, 15, who was attacked by three men with machetes whilst eating with her family and lost her right arm.

Children are the main targets of mutilation and murder in the violence against those with albinism, comprising two-thirds of documented murders and nearly all mutilating attacks since 2011 (UTSS, 2018). In some cases, it is believed that the potency of the witchcraft is enhanced both by the innocence of children and if the victim screams during amputation (UN Human Rights Council, 2013).

While the media have cited superstition and tradition as the cause of the killings and the UN Human Rights Council (2017) expert asserted that addressing witchcraft should be the priority, recent writers suggest a more complex explanation linked to poverty. For example, the rapid expansion in gold mining in Tanzania has brought social change and increased inequalities, where anything that is seen as a means of gaining easy wealth creates a market demand (Bryceson *et al.*, 2010; Bucaro, 2010; Burke *et al.*, 2014). There is evidence that both organised groups and individuals (e.g. family members who ‘sell’ their relatives) are involved, including those who have found benefits of traditional medicine in the past and who profit directly from the killings (Tanner, 2010). Powerful and wealthy members of society (who can afford to buy these charms) are implicated in the trade as end users. An important gap in the evidence base that emerges here concerns the interplay between witchcraft-related violence and poverty.

The death of a person with albinism (especially a child) who is considered to be a curse can be seen as a beneficial act, with both the birth and death of such a child going unreported (UN Human Rights Council, 2013). In 2008, the Tanzanian government declared the killing of a person with albinism as a crime punishable by death; yet despite nearly 200 arrests in the following two years, very few were prosecuted in the courts (Bucaro, 2010). Nonetheless, countries (such as Malawi, Mozambique and Tanzania) that have adopted response plans at least offer some solutions to the problem that may be effective in the longer term. Such plans include: education programmes, strengthened police structures, allocation of resources to targeted areas, research and expedited prosecution (UN Human Rights Council, 2017).

In Tanzania, albinism is seen to be the result of a curse, or as omens of disaster (Bucaro, 2010). In Namibia, people with albinism are thought of as cannibals and as contagious (Ntinda, 2009); and in Zimbabwe, as well as other countries in the region, it is believed that having sex with them

will bring a cure for HIV/AIDS (Baker *et al.*, 2010). Mothers are often blamed for their child's condition (e.g. they must have slept with a white man, or their ancestors are taking revenge). It is notable that through paternal abandonment, many children with albinism are raised by single mothers, with subsequent financial difficulties impacting on education and health (Bucaro, 2010). Others have demonstrated the more accepting belief that albinism is God's will (Baker *et al.*, 2010), and others reveal a death myth about albinism:

'When I was young, I was told that I would not die. They said I would disappear because people like me... are not like other people and do not die. I spent my childhood waiting to disappear.' (Peter Ogik cited in International Bar Association, 2017, p. 17)

Table 1 summarises some of the beliefs about albinism that are widely held.

Disability and human rights

In Africa, there is an increasing recognition that people with albinism should be acknowledged formally as disabled, primarily because of their significant vision difficulties and high fatality rates from skin cancers (UN Human Rights Council, 2018), but also in recognition of the fact that there is a lack of essential support to alleviate these issues, for example, by the provision of low vision devices and sunscreen (World Health Organization, 2010). People with albinism meet the World Health Organization's (2001) *International Classification of Functioning, Disability and Health* on a number of levels, including sensory function and skin structures. This acknowledgement is not widespread, nor is it always accepted by people with albinism themselves.

Definitions remain problematic. Thomas' (2004) development of the social model of disability recognises the significance of 'impairment effects', where the influence of an impairment on day-to-day living (e.g. a person with albinism not being able to drive because of visual impairment) is combined with the impact of societal effects (e.g. a child with albinism being denied education in order to avoid skin cancers caused by having to walk long

'In Africa, there is an increasing recognition that people with albinism should be acknowledged formally as disabled'

Table 1. Common myths and misconceptions about children with albinism in some sub-Saharan African countries

Causes of albinism	Misconceptions
Mother slept with white man (Baker <i>et al.</i> , 2010)	Contagious (Braathen and Ingstad, 2006)
Parent angered ancestors/gods (Braathen and Ingstad, 2006)	Brings bad luck (Bucaro, 2010)
Mother looked/laughed at a person with albinism (Braathen and Ingstad, 2006)	Causes sickness (United Nations Human Rights Council, 2013)
Missing top layer of skin (Lund, 2001)	Brings death (Ntinda, 2009; Brocco, 2015)
Negative beliefs	Positive beliefs
Ghosts; devils; not 'real' people (Baker <i>et al.</i> , 2010; Brocco, 2015)	Source of money as body parts can be traded (Bucaro, 2010)
Don't die, simply vanish (United Nations Human Rights Council, 2017)	Body parts bring easy wealth, good luck (Phatoli <i>et al.</i> , 2015)
Sorcerers (Phatoli <i>et al.</i> , 2015)	Gift/blessing as have magical powers to tell the future (Phatoli <i>et al.</i> , 2015)
Cannibals (Ntinda, 2009)	
Sexual intercourse can cure HIV/AIDS (Baker <i>et al.</i> , 2010; Ntinda, 2009)	
Sacrifice will appease gods (Ntinda, 2009)	

‘Recognition of the condition as a disability gives those affected a place in the world and facilitates advocacy’

distances to school in bright sunshine). Such effects would be seen as acts of disablism (Thomas, 2004; Taylor *et al.*, 2015).

Albinism leaders comment that recognition of the condition as a disability gives those affected a place in the world and facilitates advocacy (Kromberg and Manga, 2018). Moreover, as disabled people their rights under the UN Convention on the Rights of Persons with Disabilities are recognised. In the last few years, the UN has emphasised the extreme discrimination and life-threatening dangers facing people with albinism and has made a number of attempts in raising awareness about these issues (e.g. UN Human Rights Council, 2013, 2017). In addition, international standards for the protection and promotion of rights for people with albinism have been proposed (International Bar Association, 2017). Across Africa, children with albinism also have rights under the UN Convention on the Rights of the Child and the African Charter on the Rights and Welfare of the Child, both concerned with issues of discrimination, empowerment and protection. There is, however, a large question mark over the extent to which international standards in Africa actually keep children safe (Walker-Simpson, 2017). Prejudice, abuse and violence against disabled children more generally are rife in Africa (UNICEF, 2016) and it is not only those with albinism who are targeted.

An Integrated theoretical framework

We have previously proposed an integrated theoretical framework to understand the challenges for people with albinism and their families that combines Thomas' (2004) concepts of ‘barriers to being’ and ‘barriers to doing’ with a human rights approach (see Franklin *et al.*, 2018). Thomas argued that understanding and addressing disablism mean tackling both the socio-structural restrictions on disabled people (barriers to doing) and those negative social processes and practices that affect the wellbeing of disabled people (barriers to being). Using that integrated theory, we focus here on children in the current context of ritualised violence in sub-Saharan Africa. In this conceptual review, we propose that there are five interlinked sources of vulnerability for children with albinism: (1) they are children – a fact that intensifies all the other vulnerabilities faced by people with albinism; (2) they are extremely sensitive to the damaging effects of the sun due to a lack of pigmentation; (3) they are visually impaired; (4) they regularly experience social ostracism and rejection fuelled by a lack of understanding of the inherited nature of their condition; and (5) specific to some regions, children with albinism are targeted for their body parts in order to make traditional medicine. This quintet of vulnerabilities (Figure 1) makes children with albinism a group of children needing care and protection at every level.

We suggest that the ‘otherness’ of children with albinism already exposes them to discrimination and trauma, but within the current context of violence, abduction and murder, this otherness makes them and their families ever watchful in order to keep safe. The combined effects of otherness and watchfulness can have a profound effect on children's agency. Otherness may be seen as a causal state, with the effect of watchfulness, with agency as reaction or mitigation. Recent re-conceptualisations about the agency of children stretch our thinking to non-binary approaches that are relevant here, where rights and vulnerabilities are acknowledged alongside the resiliencies

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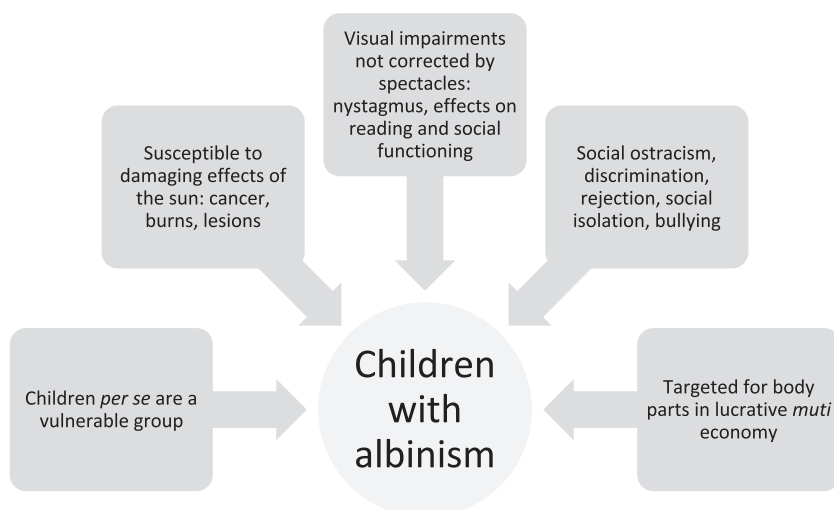


Figure 1. Children with albinism: A quintet of vulnerability.

and competencies of young people (Thompson *et al.*, 2017). Whilst the otherness within our framework has some congruence with Goffman's (1963) sociological concepts of stigma, spoiled identity and dehumanisation, Goffman's focus on the stigmatised rather than the stigmatisers separates us, as does our focus on agency.

Otherness

“‘We're being killed like animals. Please pray for us’ one albino woman sings.’ (Kikeke, 2014)

The recognition of otherness of children with albinism starts from birth by the family and the community, although children themselves will not recognise this difference until later in life. Their lives are marred by stigmatisation and rejection, lack of acceptance, perceptions of difference and limited social integration (Pooe-Monyemore *et al.*, 2012; Brocco, 2015).

African countries are not the only ones that demonstrate negative attitudes toward people with albinism, and structural discrimination and marginalisation are recognised as a global phenomenon (UN Human Rights Council, 2013). Nonetheless, we would argue that the markedly different visible appearance of children with albinism among dark-skinned communities, compounded by superstition, myths and a lack of understanding of albinism, exacerbates their ‘otherness’ in the sub-Saharan context.

Few studies have examined the negative effects of labels and terminologies used to describe people with albinism in Africa. Brocco (2015) however highlights the negative labels which he encountered that always emphasise difference and otherness. Participants in his study had all been subject to derogatory name-calling.

About half of the pupils in a sample of schoolchildren did not know why their skin was pale – it was common to believe that the top (black) layer of skin was missing or that it was a result of witchcraft (Lund, 2001). Such beliefs lead

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to significant prejudice, stigma, antagonism and rejection (Lund, 2001; Gaigher *et al.*, 2002; Poee-Monyemore *et al.*, 2012).

‘My childhood is a very sad story... Before me, my parents had another baby with albinism. They saw this baby as a curse, and would often refuse to feed it. It died of starvation. When I came along, my mother refused to breastfeed me. In her eyes, I was a creature and a curse: not human.’ (Merumba, 2017)

The educational experience of children with albinism in Africa varies, as some are taught in mainstream schools, sometimes with special resource centres attached, and some in specialist schools for disabled or visually impaired children. However, often children with albinism are not seen as worth educating because their social and economic prospects are thought to be so limited (Lynch *et al.*, 2014). The local lack of education and information about the condition unsurprisingly affects teachers and their attitudes to these pupils due to their reliance on myths and misinformation (Baker *et al.*, 2010).

Watchfulness

The profound effects of the violence against families with albinism in a number of countries in Africa are documented in media and NGO reports, although it is impossible to know how many people have been attacked or displaced (International Federation of the Red Cross and Red Crescent Societies, 2009). Referring to Tanzania, this organisation reported on the climate of fear that the violence invokes:

‘Thousands of albinos are no longer able to move around for fear of the hunters... probably the overwhelming majority of the total population of albinos... are no longer able to move around freely to work, study or tend vegetable plots... their lives are on hold.’ (International Federation of the Red Cross and Red Crescent Societies, 2009, pp. 5–6)

The threat of violence results in an increased vigilance, a watchfulness that is felt by children, their families and communities. Family members are forced to take time away from their work (often subsistence farming to feed their families) in order to escort their children to school or to other areas of the community in order to keep them safe (Allen, 2008; Burke *et al.*, 2014), with incumbent effects on employment and income. Others have taken their children out of school altogether in order to protect them (van Herwijnen *et al.*, 2016). There are reports of hiding children at home, sending children to boarding schools or camps, seeking asylum in police stations or sending children to relatives in safer parts of the country (Burke *et al.*, 2014). This vigilance does not stop at death:

‘My father spent many nights sleeping next to my sister's grave. He wanted to make sure no one came to take her body because people think you can get powers from body parts of persons with albinism.’ (Peter Ogik cited in International Bar Association, 2017, p. 46)

The Tanzanian government's initial response to the violence against children with albinism included a policy of moving these children from their family homes into special schools and camps in order to protect them (Burke *et al.*, 2014). Such forced segregation has undoubtedly resulted in fewer attacks, but it comes at a price: impoverished amenities, overcrowding, inadequate

support and incidences of child abuse. Some families have abandoned their children to these camps (Burke *et al.*, 2014).

It is not uncommon for family members, including parents, to be involved in abductions and killings (UTSS, 2018). The fear of attack is constant, as those with albinism do not know who they can trust, as illustrated in the following quotations:

'Here the situation is relatively quiet, but sometimes when outside of the village strangers call me dili [deal - referring to commercial value of body parts]. Sometimes I felt really frightened because it could happen that one of these persons intended to kidnap me. One never knows what might happen.' (Brocco, 2015, p.1151)

'I was out one evening looking for something to eat when I was ambushed by a group of men... They wanted to cut my head off to perform witchcraft... I believe my cousin was one of the men, though he denies it to this day and has never been prosecuted.' (Merumba, 2017)

Specific security guidance has been produced for people with albinism, which includes advice on: being vigilant of both strangers and family (van Herwijnen *et al.*, 2016), not travelling alone, varying travel times, buddy systems and not accepting lifts. Contrary to usual security advice, people with albinism are advised to fight and scream during an attempted abduction to increase the chances of survival.

The effects of vigilance and surveillance also extend to local leaders, who are responsible for keeping people in their community safe, but who do not always have the resources to provide safe measures for children with albinism (Mkama, 2016). Promoting the safety of children with albinism is complex and requires both individual and collective responsibility. Additionally, there are important questions to be asked as to the impact of pervasive difference and hyper-vigilance on a child's sense of esteem and self-belief; in other words, their agency.

Agency

As with otherness and watchfulness, the promotion of a child's sense of agency can be regarded conceptually as operating at different levels. At a political and systems level, an action plan formulated at the Action on albinism in Africa consultative forum (17–19 June 2016, Dar es Salaam) (UN Human Rights Council, 2016) agreed that promoting safety and agency needed foundational measures (government mechanisms) in addition to a range of prevention, protection and accountability measures. However, awareness raising and advocacy have largely been undertaken by NGOs and the media, rather than governments – and even then with only limited success (Burke *et al.*, 2014).

The societal impacts of impoverished education and employment opportunities have a bearing on the agency of young people with albinism and their ability to reach their full potential and become active and respected members of their communities. Poee-Monyemore *et al.* (2012) found that employment was correlated with higher levels of self-esteem. As one of their participants reflected:

'...mostly they [people with albinism] are unemployed... that's why I say people with albinism are not necessarily treated as normal people in all instances... it's hard for them to be employed.' (Poee-Monyemore *et al.*, 2012, p. 5)

'The fear of attack is constant, as those with albinism do not know who they can trust'

'Awareness raising and advocacy have largely been undertaken by NGOs and the media, rather than governments'

‘A direct link has been demonstrated between teachers who know how to support children with albinism and the increased self-esteem and sense of belonging of these pupils’

‘It seems somewhat paradoxical that children with albinism are rejected, feared and ostracised... while simultaneously they are... an enticing and valuable commodity’

This was also reported in a cross-sectional study based at dermatological clinics in Tanzania (Kiprono *et al.*, 2012). In a sample of 149 participants, 128 were eligible for employment, but 68 (53.1%) were unemployed. Half of both the employed and unemployed participants reported discrimination against their albinism in the workplace.

Teachers have a pivotal role. We have already described how they are subject to the same local beliefs about albinism as other people. However, they are influential and respected members of the community and if well informed can be an effective route for information about genetics and healthcare (Lund, 2001), as well as being able to challenge myths. A direct link has been demonstrated between teachers who know how to support children with albinism and the increased self-esteem and sense of belonging of these pupils (Dart *et al.*, 2010; Pooe-Monyemore *et al.*, 2012). Thus, investment in supporting and educating teachers may be important in promoting agency among this group of children.

As the mother of a child with albinism reported:

‘He also says that he is afraid of asking teachers what is written on the chalkboard because most of the time they talk to him harshly and this makes him to be more insecure in learning... he then develops a negative self-esteem, that he does not have the potential to do anything.’ (Dart *et al.*, 2010, p. 82)

From an individual perspective, insights into children's own sense of agency are limited in the African context. A small study ($n = 15$) in South Africa highlighted that young people with albinism are firmly committed to advocacy as a route to empowerment and equality (Pooe-Monyemore *et al.*, 2012). Participants in the study were all members of the Albinism Society of South Africa and emphasised the access that this gave them to vital services such as counselling and awareness raising and felt that this had a crucial role in enhancing their self-esteem. The extent to which such positive reports can be extended to all children with albinism is questionable. It does perhaps point to the power of collective action, brought about by being part of an empowering movement. Unfortunately though, these are likely to be accessible to the few, rather than the majority.

An integrated conceptual framework

Our framework is constructed around the current experiences of children with albinism that can be conceptualised as otherness, watchfulness and agency (Figure 2), and nested theoretically within disablism and children's rights. The otherness of children with albinism, as experienced by children themselves and perceived by others, incurs barriers to both being and doing (Franklin *et al.*, 2018). This otherness, resulting in abuse and violence, forces children with albinism, their families and communities to be ever watchful in maintaining protection and safety. Both otherness and watchfulness of children with albinism can compromise their agency, where internal and external responses highlight the complexity of living with this quintet of vulnerability.

It seems somewhat paradoxical that children with albinism are rejected, feared and ostracised for their otherness, while simultaneously they are required to be ever watchful because they are an enticing and valuable

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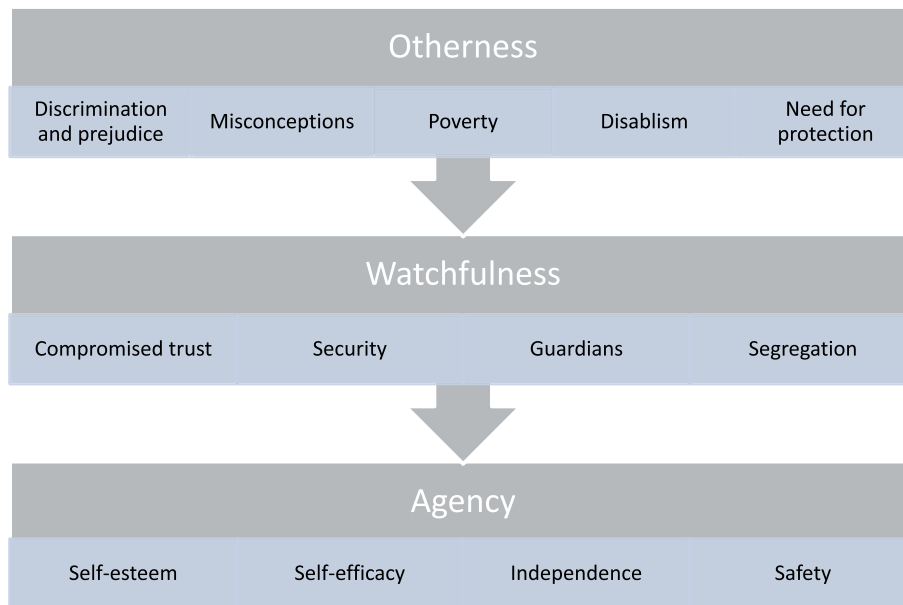


Figure 2. Experiences of children with albinism in the current context: Otherness, watchfulness and agency. [Colour figure can be viewed at wileyonlinelibrary.com]

commodity. Their otherness (in the form of body parts) is sought as powerful medicine for good luck. Capturing this irony, Torner, cited by Gilgoff (2013), mused:

‘People believe that if you are an albino, you are a magical person – so if that’s the way, why are they killing us?’

Such paradoxes though are quite common where beliefs in witchcraft, sorcery and Christianity are combined. From a Western perspective, it can be difficult to understand some of the deep-rooted superstitions and myths associated with albinism. Aside from the horror, witchcraft-related killings seem unbelievable when considered against the science of modern medicine and genetic understanding. In the context of albinism in Africa, however, the fact that something might be scientifically impossible is socially irrelevant (Tanner, 2010).

Figure 3 captures diagrammatically our conceptual framework of otherness, watchfulness and agency. Disablism against children with albinism presents barriers to their being and doing and the multiple aspects of otherness result in psychological and physical trauma. The current violent context results in the need for vigilance and constant surveillance to keep safe (watchfulness). These factors combined can affect the child’s agency, including self-esteem and security (Figure 2).

Our review has a number of limitations. While our call is for more research on *children* with albinism, we have had to rely largely on retrospective accounts of adults because of the gap in the evidence. Much of the academic literature focuses on the clinical management of vision or cancer, rather than on cultural and societal aspects. Where stigma or witchcraft-related violence is mentioned, it is rarely the immediate focus of study and our analysis is thus largely theoretical. Although children with albinism are considered disabled

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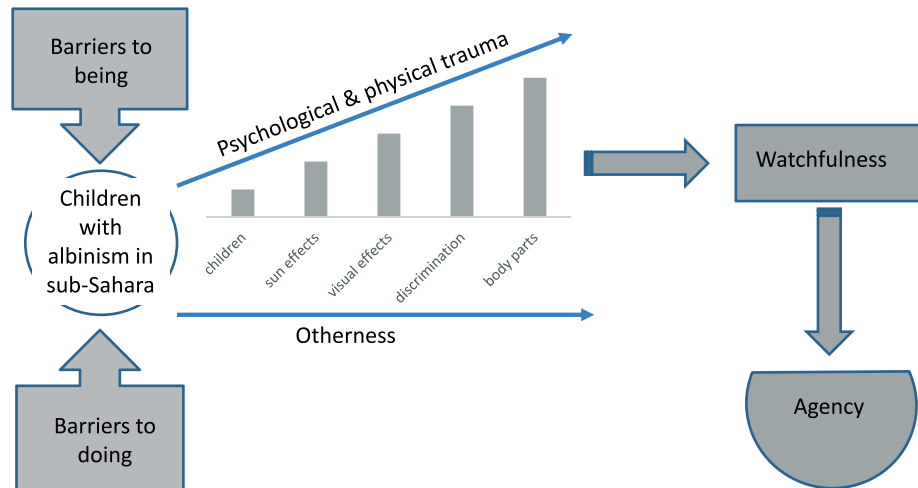


Figure 3. Children with albinism: A conceptual framework. [Colour figure can be viewed at wileyonlinelibrary.com]

children, many of the issues for children with albinism may also be experienced by disabled children more generally, but the accounts presented here provide no comparative element. Nonetheless our conceptual review unearths important insights about the lives of children with albinism in the context of witchcraft-related abuse and murder.

Conclusion

Limited understanding of the lives of children with albinism and a lack of attention given to this group of children mean that interventions to support, empower and protect them more effectively are not well understood, particularly during this ‘silent emergency’ (International Federation of Red Cross and Red Crescent Societies, 2009). Our conceptual review allows us to remain focused on the issues that matter to children with albinism and has global relevance, suggesting areas for future research and supporting advocacy.

As yet, the conceptual and theoretical bases in which to ground research studies and potential protective interventions are extremely weak. To date, there has been no clearly articulated framework through which empirical work can be guided and our conceptual review and resulting model can therefore be regarded as an important contribution to the field. As in other conceptual reviews though, this is a starting point for needed empirical work. We offer our triangle of otherness, watchfulness and agency as a platform for research on which to build and enhance our understanding of the lives of children with albinism in the sub-Saharan.

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