Introduction: Changing Narratives of Albinism in Africa

Charlotte Baker and Elvis Imafidon

Oculocutaneous albinism is a recessive genetic condition which is characterised by a reduction or lack of pigmentation in the hair, skin and eyes of people with albinism. This results not only in visual impairment and the vulnerability of skin to sun damage and skin cancer, but can also lead to the stigmatization and social marginalization of people with albinism because of their visible difference, particularly in sub-Saharan African contexts.[1] The beliefs and stereotypes that continue to be attached to albinism are one of the greatest impediments to a person with this condition taking full part in society. These beliefs range from misconceptions and stereotypes to traditional and contemporary myths, and sit alongside varying levels of understanding and acceptance of biomedical explanations for albinism.[2] At the most extreme, these beliefs are manipulated for economic gain, resulting in the attacks on people with albinism for their body parts mentioned above. However, despite the focus in the media, advocacy and scholarship on the threat that this trade in body parts poses to people with albinism, a far bigger danger is exposure to solar ultra-violet radiation, which results in sun damage and a significant increase in the risk of skin cancer in people with albinism. As Sian Hartshorne and Prashiela Manga remark, oculocutaneous albinism causes a reduction in, or lack of production of the pigment melanin, which makes the skin more susceptible to sun damage and increases the risk of skin cancers.[3] Avoiding exposure to the sun, wearing protective clothing and using sun creams can reduce risk, but a lack of access to information, to these material means of protection, and to appropriate medical care means that many people with albinism living in sub-Saharan Africa lose their lives to skin cancer before the age of 40.

The attention of the international community was first drawn to the challenges faced by people with albinism in 2008, as reports began to emerge of attacks on people with albinism in Tanzania for their body parts.[4] To date, more than 600 attacks on persons with albinism, including over 200 killings, have been recorded by the NGO Under the Same Sun in 27 sub-Saharan African countries.[5] People with albinism have been killed or mutilated and graves have been desecrated to obtain body parts. Alleged to bring wealth or success, they are used in rituals, or dried and ground, put into a package to be carried, secreted in boats, businesses, homes or clothing, or scattered in the sea.[6] As Jean Burke et al. remark, between 2008 and 2011, reports of escalating violence against people with albinism in Africa, and

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[1] While numbers vary, it is estimated that in Europe and North America, 1 in every 17,000 to 20,000 people have some form of albinism. However, albinism is much more prevalent in sub-Saharan Africa, with estimates of 1 in 1,400 people with albinism in Tanzania and a prevalence of 1 in 1,000 reported for select populations in Zimbabwe and for other specific ethnic groups in Southern Africa. 'Persons with Albinism', Report of the OHCHR, A/HRC/24/57 12 September 2013 https://undocs.org/A/HRC/24/57

[2] Charlotte Baker, Patricia Lund, Richard Nyathi and Julie Taylor, 'The Myths Surrounding People with Albinism in South Africa and Zimbabwe', *Journal of African Cultural Studies* 22.2 (2011), 169-181.

[3] Sian Hartshorne and Prashiela Manga, 'Dermatological Aspects of Albinism' in Jennifer Kromberg and Prashiela Manga (eds), *Albinism in Africa* (Elsevier 2018), pp. 121-134.

[4] Vicky Ntetema, 'In Hiding for Exposing Tanzania Witchdoctors', *BBC News*, 24 July 2008 http://news.bbc.co.uk/2/hi/africa/7523796.stm

[5] Under the Same Sun http://www.underthesamesun.com (Accessed 4 April 2021)

[6] UN Human Rights Council, 'Report of the UN Independent Expert on the enjoyment of human rights by persons with albinism', Ikponwosa Ero, 2017. A/HRC/34/59.

particularly the United Republic of Tanzania, became prominent in the international media.[7] These narratives drew attention to the vulnerability of people with albinism and their need for assistance. However, what is particularly notable in the news articles reviewed by Burke et al. is that while some voices are represented extensively in the news articles, with politicians and government officials quoted the most, followed by leaders of albinism associations and police, individual people with albinism are quoted frequently, suggesting that they are more often spoken for.[8]

Cultural representations of albinism are only now beginning to shift away from portrayals of people with albinism as voiceless, vulnerable or marginalized figures that have characterized many news reports, literary representations, films, photographic images and advocacy materials in the last decade, and towards representations of people with albinism as individuals, role models and advocates. While the challenges faced by many people with albinism in sub-Saharan Africa have not diminished, attitudes are beginning to shift and the narratives attached to albinism both reflect and have contributed to informing this change. Increasingly, perceptions of albinism are being influenced by the narratives produced by the awareness campaigns of non-governmental organizations (NGOs), humanitarian institutions and international organizations such as the United Nations Human Rights Council, as well as by the re-presentation of albinism in the arts and the media.

The chapters in this edited volume range across traditional beliefs, literary fiction, radio, music, photography, film and the arts for public engagement to explore narratives of albinism across different cultural forms in sub-Saharan Africa. The contributors share a focus on the power of narratives to shape understandings of albinism in Africa. They aim to capture the shifting narratives of albinism and to take account of their real-world effects and their implications. As such, the volume sets out to demonstrate that all forms of representation have an important role to play in building sensitivity to a range of issues related to albinism amongst national and international audiences and in effecting change, while also underscoring the ever-present dangers of misrepresentation.

Changing Narratives of Albinism

The complexity of albinism, its various understandings, and the beliefs and prejudices associated with it have made an inspiring subject for story tellers, writers of literary fiction, film-makers, playwrights and journalists. Albinism offers cultural-producers rich subject matter for their novels, films, plays and newspaper articles. However, in turn, their portrayals of albinism raise important questions about the power of representation. Stuart Hall suggests that there are three general approaches to the question of the work done by representation. The 'reflective' approach views meaning as residing in the person or thing in the real world, and that a representation such as narrative 'reflects' that meaning. The 'intentional' approach sees meaning in the control exercised by the producer of a representational form such as narrative who uses representation to make the world 'mean', while the 'constructionist' approach considers meaning as being neither in the control of the producer nor the thing being represented, but instead identifies the thoroughly social nature of the construction of meaning, the fact that representational systems, rather than their users and objects, allow

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[7] Jean Burke, Theresa J. Kaijage, and Johannes John-Langba, 'Media analysis of albino killings in Tanzania: a social work and human rights perspective', *Ethics and Social Welfare* 8.2 (2014): 117-134.

[8] Burke et al. 'Media analysis of albino killings in Tanzania', 119.

meaning to occur.[9] We are interested here in the ways in which narratives reflect meaning and in the meanings invested in narratives by cultural producers, while acknowledging that, as Paul Cobley argues, although human beings have constantly told stories, presented events and placed the world into narrative form, 'even the most "simple" of stories is embedded in a network of relations that is sometimes astounding in its complexity'.[10]

Susan Benesch's notion of 'dangerous speech' invites us to think about the potential implications of engaging different narratives of albinism in cultural representation.[11] Benesch coined the term 'dangerous speech' after observing that fear-inducing, divisive rhetoric rises steadily before outbreaks of violence and that it is often uncannily similar, even in different countries, cultures and historical periods.[12] For Benesch, words become a justificatory mechanism that makes violence acceptable, and by this she means both the threat of violence, as well as actual psychological and physical violence.[13] While Benesch's work focuses on mass violence and genocide, it provides a useful critical lens through which to consider narratives of albinism and the potential of shifting them, particularly as regards the drivers for dangerous speech, which can make violence seem more acceptable. One of these is dehumanization, a process which defines the experience of many people living with albinism in sub-Saharan Africa. While dehumanization takes different forms, essentially it denies human-ness - characteristics that are uniquely human and those that constitute human nature.[14] At its most damaging, dehumanization can become an everyday social phenomenon that is rooted in ordinary social interactions. Denying human attributes to others represents them as objects, making them seem less than human and thus not worthy of humane treatment. This makes it easier to target them, Benesch contends, leading to increased violence, human rights violations, even genocide.[15]

One of the most apparent ways in which people with albinism are marked apart is through language, as the terms used to describe them serve as a daily reminder of their difference. People with albinism are often described in animalistic terms, or with words that express the monetary value of their body parts, point to supernatural associations, or highlight the visible difference of their skin. Derogatory terms such as *isishawa* (a Zulu name for a person who is cursed), *zeru zeru* (ghost-like in Swahili) and 'dili' ('deal' in Tanzania) are adopted to emphasise the physical difference of people with albinism, their lack of humanity, and their monetary value.[16] However, people with albinism are also dehumanized through recourse to beliefs, stereotypes and myths to explain albinism.[17] The stigmatization and ostracism that result from the web of beliefs surrounding the condition have a profound influence on people with albinism from the moment of their birth until their death: Babies are born with albinism because of their mother's unfaithfulness; children with albinism are

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[9] Stuart Hall, ed. *Representation: Cultural representations and signifying practices* (London: Sage, 1997) pp.24-25.

[10] Paul Cobley, *Narrative* (London: Routledge, 2014), 2.

[11] Susan Benesch, Dangerous Speech project, https://dangerousspeech.org [Accessed 5 June 2021].

[12] Benesch makes clear that although it is difficult to draw a clear line between a single speech act and an act of violence, it is usually possible to draw a causal link.

[13] For Benesch, the term 'speech' encompasses every form of human expression, including speech, text or images, which are produced or reproduced in the cultural forms that we are interested in here.

[14] Haslam N. 2006. Dehumanization: an integrative review. Personal. Soc. Psychol. Rev. 10:252–64

[15] Susan Benesch, Dangerous Speech project, https://dangerousspeech.org [Accessed 5 June 2021].

[16] For further reading, see Giorgio Brocco's study 'Labeling albinism: language and discourse surrounding people with albinism in Tanzania', *Disability & Society* 30.8 (2015): 1143-1157.

[17] Baker, Lund, Taylor and Nyathi.

not intelligent and will not benefit from education; albinism is contagious; people with albinism will necessarily have children with albinism; people with albinism are intermediaries between the worlds of the living and the spirits; people with albinism do not die.[18] Such erroneous beliefs affect not only the family and community lives of people with albinism, but also interfere with their access to education, employment and marriage.

In the opening chapter to this volume, 'Challenging Traditional Understandings: Embedding Accurate Knowledge of Albinism in African Cultures', Elvis Imafidon addresses the impact of traditional understandings of albinism in African cultures, arguing that the sustenance of false cultural interpretations and understandings is a source of harm, and results in the perpetuation of prejudice and discrimination against persons with albinism in African communities. He proposes that alternative repositories of knowledge must be explored further in embedding accurate knowledge of albinism in members of African communities, but not without first tackling indigenous knowledge systems and including indigenous repositories of knowledge and avenues of knowing in these efforts.

The beliefs and stereotypes associated with albinism are often reproduced in oral and written African literatures and films, in which characters with albinism are frequently represented as having magical powers, as vulnerable victims, or as symbolic figures. For example, Nollywood films play on the fictional potential of the beliefs associated with albinism. Tunde Kelani's *Ti Oluwa ni Ile* (2013) portrays the luring of a character with albinism into the forest for ritual killing because of the traditional beliefs associated with albinism, but makes no real attempt to challenge them, while other more recent Nollywood movies like *The Albino 1* and *2* (2018) much more overtly sensationalize albinism. Kolawole Olaiya examines the evolution of representations of albinism in selected Nigerian movies in his chapter 'Debunking Stereotypes or Reinforcing Them? The Representation of Albinism in Three Nigerian Films'. The chapter examines the different ways in which directors have used film to creatively engage with educating the public about the genetic and social basis of albinism and the challenges confronting people with albinism, demonstrating how film can influence perceptions of people with albinism.

Authors of literary works have also responded in diverse and interesting ways to the increasingly visible situation of people with albinism. The Congolese writer Éveline Mankou describes how she was inspired to write her 2012 novel *Instinct de survie* when she learned of the violent attacks on people with albinism in an interview, remarking: 'Un jour je lisais des articles sur internet et là, j'ai découvert des choses abominables, des atrocités sur le sort des albinos. Comme une révélation, je me suis dit il fallait faire quelque chose'. [One day I read articles on the internet and there I discovered awful things, atrocities against albinos. Like a revelation, I said to myself that I had to do something].[19] As Charlotte Baker remarks in her chapter 'Literature as Advocacy: Fictional Representations of Albinism in African Contexts', Mankou's novel belongs to a new wave of literary representations of albinism that treat their protagonists in less symbolic terms, preferring realism and pointing explicitly to challenges confronting people with albinism in parts of sub-Saharan Africa. Her chapter examines contemporary representations of albinism in prose fiction by African writers published in the late 20th and early 21st century, asking to what extent they can be considered examples of a literary form of advocacy with the capacity to bring about social change. Christopher Hohl's chapter reveals that there has also been a notable shift in representations of albinism in photography too. His contribution 'Albinism between Stigma and Charisma' compares two

[18] Baker, Lund, Taylor and Nyathi.
[19] http://tribune2lartiste.com/livres/linstinct-de-survie/ [Accessed 6 February 2018]

photographic images of people with albinism taken in South Africa and traces their transnational circulation as well as local interpretations. In the process, Hohl's chapter elaborates different conceptions of the hypopigmented bodies of people with albinism, reminding us of the power of visual imagery and showing how their staging and interpretation varies between framings, attributions and aestheticization.

The Arts for Advocacy and Social Change
The advocacy of albinism associations and civil society has been crucial to bringing about changes locally and nationally to address the challenges faced by people with albinism. At the same time, the work of UN Human Rights Council and the Independent Expert on the Rights of Persons with Albinism, national governments and NGOS has been key to raising the visibility of albinism nationally and internationally, enhancing understandings and addressing the practical needs of people with albinism, for example, in providing sunscreens, health care and educational opportunities. However, there is also a need to bring about a change in understanding on the level of public consciousness, and it is here that cultural representations have an important role to play in shifting narratives of albinism. All cultural forms can contribute to building sensitivity to the issues related to albinism amongst national and international audiences, and it is encouraging to see that the human rights challenges faced by people with albinism across many African nations are increasingly becoming a focus of writers, storytellers, film makers and musicians across the continent. At the same time, an increasing number of NGOs and advocates are taking account of the power of representation and turning to the arts to convey important messages about albinism to audiences locally and internationally. However, the use of these forms of cultural representation raises further questions, which are explored by some of the contributors to this volume.

Giorgio Brocco's chapter 'Sparks of Otherness: Producing Representations of Albinism in Africa in Documentary Films from the Global North' examines documentary films produced by Western media companies. Brocco sets out to highlight how these media productions represent the social, political and individual aspects of living with albinism, and the phenomenon of the violence against people with the condition in Tanzania and other African countries, while revealing in which symbolic ways these media productions seek to illustrate African social and political contexts and their tendency to reproduce narratives of people with albinism as victims who lack agency. Extending this discussion, in his chapter 'Voices that Stand: The Power of Film for Advocacy on Albinism in Africa', Sam Clarke traces a rich lineage of films featuring albinism, interrogating the ability of this 'ambivalent weapon in the arsenal of those seeking to defend the rights of people with albinism in Africa' to steer cultural narratives around albinism and to generate changes, not just in representation but also in reality.

Albinism organizations and NGOs have also adopted the arts as a way of communicating key messages to communities. Art, music, dance, storytelling and theatre are being used by academics and advocates to articulate the scientific facts about albinism to audiences in Tanzania. Tjitske de Groot et al.'s chapter 'Reducing albinism related stigma among primary school students through a theatre intervention in Tanzania' explores the potential of theatre to enhance understandings and reduce stigma. The chapter discusses the *Haki Yetu* (Our Rights) theatre tour, which aimed to raise awareness on albinism in Tanzanian primary schools by improving knowledge and reducing stigmatizing attitudes. Discussing a recent cross-disciplinary collaboration between artists and scientists in Tanzania, Christiane Essombe, Patricia Lund and Jon Beale's chapter 'Science, Art, Community: Building Interactive

Understanding of Albinism in Tanzania' demonstrates the potential of the arts to communicate scientific knowledge about albinism to communities. They examine how innovative community engagement methods can be mobilized to explain the genetic origin of albinism, thereby challenging superstitions associated with discrimination and violence against people with albinism.

People with albinism are also adopting creative forms to reach a larger audience with positive messages about albinism though self-advocacy and music has been one of the most powerful tools by which to achieve this. Salif Keita in Mali, John Chiti in Zambia and Lazarus Chigwandali in Malawi are among those who have used music for advocacy. John Chiti describes how he uses his music 'to reach the public and send empowering messages. I raise awareness by composing songs about albinism and encouraging people with albinism to enter the limelight and become role models like me'.[20] In his chapter on albinism and music in Malawi, Ken Junior Lipenga explores the musical response to the attacks and killings of people with albinism in Malawi. Focusing on the role of music in highlighting violence against people with albinism, Lipenga considers how the songs he discusses demand empathy and recognition of shared humanity.

Changing Narratives of Albinism

The critical analysis of all forms of representation elucidates underlying assumptions about albinism, while attention to narrative offers us the possibility of opening up new discursive spaces which have the potential to evoke far-reaching social change. The chapters in this volume demonstrate that the challenges currently faced by people with albinism in many African nations are increasingly becoming a focus of African writers, storytellers, artists and filmmakers across the continent. At the same time, it highlights the innovative ways in which NGOs and advocates are taking account of the power of representation and engaging the arts to convey important messages about albinism to audiences locally and internationally.

The term 'Changing Narratives' in the title of this volume refers to a recognition that discourses and representations of albinism are changing, but it is also a call for further change. Benesch argues for the positive value in identifying 'dangerous speech' and sensitizing people to it. Awareness of all these different forms of dangerous speech enables us to ensure that people are less influenced by it and more able to counter it. While there has been action at international, national and local levels to raise awareness of albinism and particularly to highlight and address the human rights abuses against people with albinism, there must also be a re-evaluation of the ways in which we speak about, write about and represent albinism. By being critically conscious of the ways in which we represent albinism, we can prime audiences to be aware of and educated about albinism. We can counter dangerous speech and instead open up understandings of albinism, ensuring that the voices of those who are directly affected are heard and in the right contexts.

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