

People with Albinism and Humanitarian NGOs in Tanzania: Identities between Local and Global Worlds

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This photo essay discusses the interactions between international and national non-governmental organizations (NGOs) and governmental organizations on the one hand, and local populations and people with albinism on the other, in Tanzania. From the mid-2000s onward, international attention started to be drawn to the aggressions toward, and the murders of, people with albinism in the north-western part of Tanzania (Ntetema 2008). To date, around 74 individuals with the condition are said to have lost their lives (Smith 2015; Mlacha 2015; Shigongo 2015). Since the increase in attention to such issues, national health organizations as well as international NGOs have begun to carry out awareness campaigns on behalf of people with albinism. At the same time, they have implemented humanitarian aid programs, distributing sunglasses and sunscreen. Some organizations have also distributed grants and scholarships to allow people with albinism to pursue their education.

The following essay presents connections between these supra-local actors who are participating in the global flow of (bio)medical and human rights campaigns about albinism, and persons with albinism themselves who, instead of simply being passively exposed to such discourses, actively appropriate them in the making and remaking of their identities. In this regard, people with albinism capitalize on the global flow of (bio)medical and human rights campaigns on their behalf in order to enhance their inclusion within their families and local communities, while attempting to redefine ideas of normalcy and able-bodiedness in Tanzanian society at large. At the same time, this process of appropriation incorporates previous conceptions of albinism derived from religious explanations, especially at the rural level, which has not been deeply reached by governmental and international awareness campaigns.

Oculocutaneous Albinism, which is the most widespread type of albinism, is a congenital condition that phenotypically appears as hypopigmentation of the skin, hair and eyes. Around the world, as in the USA and Europe, approximately one individual in 17,000-20,000 persons is estimated to live with albinism (Wan 2003). In some African countries, the percentage is notably higher than the global average, at around one in 4,728 in Zimbabwe (Lund 1996) and one in 3,900 in South Africa (Kromberg and Jenkins 1982). In Tanzania, according to the official National Population and Housing Census of 2012 (National Bureau of Statistics 2014), there are 16,477 people with albinism, which accounts for around 0.04 percent of the total population of 44,928,923 (ibid. 2014). A review carried out by the World Health Organization (WHO), though based on incomplete data, found the prevalence of people with albinism in the country to be one in 4,000 individuals (Hong et al. 2006: 3). Some of the informants in my study from the Tanzania Albinism Society (TAS) claimed, however, that the number of people with albinism is much higher, estimated at around 170,000 individuals.

Research Methodology

As part of a larger ethnographic study conducted in Kilolo district, Tanzania, over the past two years I have examined the life experiences and subjectivities of people with albinism, as well as ideas and discourses circulating on albinism in the country. For this purpose, I have carried out fieldwork in the villages of Kilolo district in Iringa region, as well as in Ilula (Kilolo district), Iringa town and Dar es Salaam.

This photo essay focuses on the way in which humanitarian aid programs and awareness campaigns on behalf of people with albinism are configured by international NGOs such as Under the Same Sun (UTSS) and Tulime Onlus; national organizations such as TAS; and national hospitals such as the Kilimanjaro Christian Medical Center (KCMC) in Moshi. Furthermore, the essay aims to show how the "material" activities carried out by international and national organizations have shaped and interact with local perceptions and practices surrounding albinism.

While several photos were taken while I was collecting information on people with albinism exclusively in the context of my ethnographic fieldwork (photos 2, 3, 4, 6, 7), others (photos 1, 5, 8, 9, 10) were taken during the time when I worked as a researcher-cum-employee for Tulime Onlus, one of the organizations active in providing aid for people with albinism in Tanzania. The pictures therefore highlight not only the existing interactions between NGOs and people with albinism, but also my own positionality as an anthropological researcher who was simultaneously employed as an NGO staff member.

Informed Consent, the Researcher's Positionality and Pictured Subjectivities

My shifting position as both a researcher and an NGO staff member meant that I obtained the informed consent of all the informants for taking the pictures twice. All of the participants shown in the photos were informed about the possibility that the photos might be published online, specifically on the Tulime Onlus website, or in my scholarly publications. Because of this, I initially used the same informed consent form used by Tulime Onlus. Later on, however, I decided to deliver a new informed consent form to all of the individuals pictured in the photos, which was specifically designed for my ethnographic research.

Most of the participants consented to be photographed and to the possibility of their photos being published without concern. In the case of the children, informed consent was first asked from them personally and then from their guardians; this was often a grandmother or, alternatively, one or both of their parents. The information regarding the publication of the photos, as well as the informed consent forms of Tulime Onlus and my specific research, were written in both Kiswahili and English.

Even though the pictures taken during my employment with Tulime Onlus are my own property, I nevertheless obtained permission from the NGO to use them. Upon my return to Tanzania in February 2015, I reached out to the people in the photographs again and obtained their consent

to publish the pictures in the context of my ethnographic research (though I have not been able to reach those in photos 8, 9 and 10, whose consent had already been obtained during my employment with Tulime Onlus). This time, I used two types of informed consent form, one for the adult participants and another specifically for the children and their parents, both with the logo of the Freie Universität Berlin (under whose auspices I am conducting the ethnographic research). Before signing the informed consent form, all of the participants were informed about the kind of research I was carrying out, for which institution I was collecting the data, where the photos would be published and, finally, the aim and relevance of the research.

The above formal description of the informed consent process only partially covers the nature of my anthropological research and the way in which most people reacted to my requests to take their picture for the purpose of academic research and/or humanitarian work. Beyond this description, subjectivity, as the individual inner world made up of the feelings and experiences of individual persons (Biehl, Good and Kleinman 2007), is a pivotal concept that is necessary to engage with in order to understand how people with albinism responded to my request to photograph them in a context that has been shaped by the highly ambivalent dynamics of mass image production in a globalizing world; something that they were aware of to differing degrees. Thus their responses, whether positive or negative, and the explanations that followed, gave persons with albinism the chance to mediate between their own subjective sense of “being portrayed” (Irving 2007) and the global attitude of “getting pictured”; an opportunity that was present during the ethnographic fieldwork, but was not offered them when I performed the role of NGO worker, which established a more explicit hierarchy between us. When I worked for the NGO Tulime Onlus, the people I met did not have the chance to explain why they did or did not accept to be portrayed as I was mainly worried to get a positive or negative answer to my request from them. Neither did I ask them for the reasons for their responses nor did one of them go into the topic in depth.

In this photo essay, only ten pictures are included. One reason for this lies in the fact that not all of the adults and children with whom I talked during my research agreed to be portrayed. Some of the persons with albinism who refused to be photographed took this decision partially for the reason that they felt ashamed of their physical appearance. Others did not want their image to be published and seen by unknown individuals all around the world. Nevertheless, the majority of people with albinism decided to let me take their pictures, for different reasons. One woman stated that she was glad to appear in “my research book” (*report yangu ya/kitabu changu cha utafiti* [1]) so that people from other countries can understand that many people with albinism live in Tanzania and that “not all Tanzanians look like having black skin (*ngozi nyeusi*).” At the same time, she asked for make-up and put on a black wig before being photographed. Eric Mgohamwende [2] from TAS stated that he did not have any problem with being portrayed, as he was very proud of what he has been doing for people with albinism in his country. He remarked that “Europeans should become aware of our strength (*Wazungu wengine lazima wajue bidii zetu*) in fighting against the [social] marginalization attached to my brothers (*ndugu zangu*).” The parents of one child with albinism explained that I could photograph them and their child so that “other individuals from outside and inside the country can look at the poor living conditions in which many persons with albinism live” and consequently “they can help us (*wataweza kutusaidia*).”

NGO Responses to Albinism in Tanzania

The rise in the number of NGOs since the 1980s in the realm of global development has been extensively documented (Edwards and Hulme 1992; Hulme and Edwards 1997; Lewis 2005). Today, NGOs are important and often large-scale actors in the landscape of international development. Alongside the more familiar roles of service delivery and campaigning, NGOs have also become active in a complex range of development activities that include democracy building, conflict resolution, human rights work, policy analysis, research and information provision (Lewis 2005a). Furthermore, NGOs are seen by policy makers as having specific advantages in organizational terms, concerning their supposed flexibility, commitment and community responsiveness (Lewis 2001). The photos in this essay and the explanations related to them highlight how international and national (non-)governmental organizations have become emblematic of “localized modernities” (Arce and Long 2000), in which development and informational processes are fragmented, reinterpreted and locally appropriated. For instance, photos 4, 5 and 6 show ways in which people with albinism, their relatives and community members get in touch with (bio)medical and human rights information spread by NGO and global agents. As I will demonstrate below, however, such information is often reinterpreted in the light of local moral-religious explanations of their own condition.

Among the organizations that operate on behalf of people with albinism in Tanzania, Under the Same Sun (UTSS) is one of the most recognized NGOs internationally (photo 2). UTSS is a Christian/Pentecostal NGO based in Canada, founded in 2008 by its current CEO Peter Ash, a wealthy entrepreneur living with albinism. Since its foundation, the organization, whose Executive Director is Vicky Ntetema, the first journalist who addressed the killings of people with albinism, has been committed to conducting awareness campaigns related to people with albinism throughout the country by distributing flyers and desk posters, as well as organizing public meetings mainly in the rural north-western part of Tanzania. Aside from such activities, UTSS has also provided young boys and girls with albinism with around 320 scholarships, allowing them to pursue their studies.

At the national level, TAS is the national organization that deals exclusively with and is run by people with albinism in Tanzania. The organization has branches in every Tanzanian region and district. Photo 3 portrays Eric Mgohamwende, the TAS representative responsible for people with albinism in Kilolo district. TAS has a longer history than UTSS, having been created in 1978 by a German physician, Prof. Henschke, a cancer specialist who at the time was working at the Muhimbili National Hospital and at the Ocean Road Cancer Hospital in Dar es Salaam. Henschke collaborated with Nicholas Lamek Ali, a person living with albinism, to create an organization that could assist with the medical and societal problems faced by people with the congenital condition.

Every year, TAS, supported by the Tanzanian government and sponsored by international donors, organizes a National Albinism Day, which in 2014 was celebrated in Dar es Salaam from May 2nd to May 4th (even though the very National Albinism Day was only on May 4th). In

2015, this gathering of people with albinism from all over the country will be held on June 13th, as the UN General Assembly has declared that date to be International Albinism Awareness Day. Similar to UTSS, TAS also aims to conduct awareness campaigns on behalf of people with albinism, even though, due to the lack of economic resources, the content of its activities as well as its financial abilities depend largely on its international donors and other related organizations, such as [Standing Voice](#).

The photos below (4, 6) portray the work of one of the volunteers of the Kilimanjaro Christian Medical Center (KCMC) in Kilolo district on behalf of people with albinism. The KCMC hospital was founded in 1971 by the Good Samaritan Foundation and is, together with the Ocean Road Cancer Institute and the Muhimbili National Hospital, one of the most important Tanzanian health centers specialized in cancer and venere-dermatological treatments. The KCMC hosts the Regional Dermatology Training Center (RDTC), a dermatological unit established in 1992 as a partnership between the Tanzanian Ministry of Health and the Good Samaritan Foundation. The center, promoted by the International Foundation for Dermatology (IFD) and associated with the Kilimanjaro Christian Medical College, carries out a program in collaboration with UTSS called "Kilimanjaro Sun Care Cream," supporting the needs of people with albinism and training them in the preparation of sunscreens (Hay 2013).

Within Kilolo district, Sista Laurentina Bukombe, a sister from the St. Thérèse of the Child Jesus Order, who has a diploma in venere-dermatology from the KCMC and works in the health center of Mtandika, is in charge of these activities in her function as the KCMC person responsible for people with albinism in the district. As she stated in an interview, her work mainly concentrates on providing dermatological assistance to people with albinism in the area and delivering sunscreens provided by KCMC. About every three months, she organizes public meetings in order to distribute sunscreen and check the skin of people with albinism. As the referent for the hospital in Moshi, she is also responsible for annually drawing up a list of people with albinism in need of surgical intervention to remove or treat a skin cancer.

Since 2012, Tulime Onlus, an Italian NGO, has been running a project within Kilolo district entitled "No More Discrimination against People with Albinism" (photos 1, 5, 8, 9, 10). The project is partially financed both by the European Union (EU), through funds coming from the European Voluntary Service (EVS), and the Italian Waldensian Protestant Church. The project is being conducted in three phases. While the first two phases aimed to carry out a census of people with albinism in the district, and provide them with sunscreen, hats and graduated sunglasses (photos 1, 9, 10), the third phase aims to deliver an awareness campaign on albinism and disability throughout the district's 38 secondary schools (photo 5).

Perceptions of Derservingness and Discrimination: Shaping and Reshaping New Identities in the Context of NGOs

The photos in this essay mirror the extent to which local service delivery, as well as the campaigns to spread (bio)medical explanations and enhance the inclusion of people with

albinism carried out by national and international organizations, have influenced perceptions of albinism at the local level. This is particularly the case in settings where individuals have been strongly exposed to humanitarian actions and/or have easier access to mass media and public debates. In such instances, people with albinism and their family members have publicly started to present themselves as being in urgent need of special aid from humanitarian NGOs. Furthermore, as the majority of people with albinism live in conditions of extreme poverty in rural settings and cannot carry out agricultural activities (the main occupation and source of income in rural areas), many of them emphasize their poor socio-economic condition and the stigma attached to them. This is even the case among those who have received education and live in urban areas.

Such arguments were brought forward, for instance, when I talked to people with albinism during the data gathering for the census and the project “No More Discrimination against People with Albinism” that I conducted on behalf of Tulime Onlus (photos 8, 9, 10). Some people with albinism underlined how they did not have any other way to survive apart from asking for the support of their families and friends, as participation in agricultural work was denied them due to the high incidence of skin cancer caused by sun exposure (photos 9, 10). Others claimed that even though they were educated, they did not have as many job opportunities as “black skinned” persons. Reasons for this were ascribed to the discriminating discourses and stigmatizing ideas attached to people with albinism that were perceived to be shared by the majority of Tanzanian employers, which held that they were not “intelligent enough” to accomplish simple work tasks or that they could not be employed in shops because customers would not buy commodities sold by people with albinism. In a similar vein, I had several conversations with parents who repeatedly stressed their fear of their children or relatives with the condition being killed by “witchdoctors” (*waganga wa kienyeji*) or by skin cancer, the two main causes of death among people with albinism.

In reporting the above statements derived from my work experience as an NGO staff worker, I do not intend to claim that all or a part of the issues connected to having albinism in Tanzania are not “true.” However, I do wish to highlight that such claims for support are brought forward primarily in the context of NGO interventions, where persons with albinism and their family members mainly emphasized the hurdles and difficulties they were facing, in the hopes of receiving some sort of economic “help” for the development (*maendeleo*) of their own lives. This form of (self-)representation has been readily taken up by the media, which, in order to draw public attention to the killings of people with albinism, has tended to portray people with albinism mainly in pitiful terms, and also by NGOs, which hope to attract new donors and increase the interest of their national and global audiences. Following this logic, less attention is devoted to the fact that the flow of humanitarian discourses and media campaigns has also shaped new political identities for people with albinism, as well as renewing existing ones in the national and international political arena (photos 2, 3, 6 and 7). Furthermore, such statements conceal the fact that in the villages of Kilolo district, people are largely unaware of the biomedically defined condition of albinism. The majority of them, including people with albinism themselves, explain the congenital condition by resorting to religious-moral discourses of both Christian and Muslim origin, according to which albinism is a condition brought about through God's will. Therefore, even though NGOs and governmental organizations, as well as media debates on the theme, convey new discourses on albinism, local idioms and terms related to the condition remain alive

– though they have become increasingly intertwined with (bio)medical discourses and definitions at different levels.

Disabilities and Group Identities: From Religious-Moral Discourses to Processes of De-Stigmatization

Many community members and families of people with albinism who live in the city of Iringa (the capital city of Iringa region, of which Kilolo district is a part) or in highly populated villages near the urban setting consider albinism a condition brought by God, which manifests as a lack of vitamins or iron (*madini*) in the blood. Furthermore, albinism is sometimes considered the manifestation of a curse (*laana*) attached to the family with a child with albinism because of the past misdeeds of one of its members. At the same time, such explanations were challenged by people with albinism themselves, who claimed that those individuals who stigmatized them for their physical appearance ran the risk of being punished by their (Christian or Muslim) God for their behavior. Hence, moral-religious explanations for the origin of albinism were being actively modified, appropriated and reinterpreted. Furthermore, the religious-moral discourse was used by people with albinism in order to intensify their inclusion in the community and demystify stigmatizing behaviors towards them.

Such processes of destigmatization were sustained by the fact that people with albinism have started to identify themselves as disabled individuals following the awareness campaigns carried out by national and international organizations, which have become further connected to media debates on the killings of people with albinism in the country and the strengthening of already existing self-help groups and organizations (photo 6, 7). In this regard, the self-identification as “disabled” helps people with albinism to obtain a recognizable social status within society and explain to others why they cannot carry out work and activities under the sun in the same way as “normal” individuals (*watu wa kawaida*).

Organizations such as TAS make claims for new rights and safeguards for people with albinism in Tanzanian society, shaping new political identities and renewing existing ones in the national and international political arena (photos 2 and 3). For instance, pushing for the political recognition of people with albinism, both as individuals with a disability and at the same time as persons who should be fully included in society (through inclusive education and equal job market opportunities), is one of the positions that TAS, UTSS and other organizations are carrying forward. Aside from the identity of deservingness (of education, employment, etc.), people with albinism have also developed a group identity that emphasizes the positive aspects of living with albinism and disability. This identity came out in a conversation I had with a member of the Ilala TAS branch in Dar es Salaam, who affirmed that “[In the years] before all these awareness campaigns and the phenomenon of the killings, people with albinism used to ignore each other. (...) Nowadays, it is different!” The difference between past and present experiences of living with albinism is, according to this interviewee, the fact that people with albinism today meet each other during public meetings held by NGOs on their behalf; share experiences of their problems; and organize humanitarian activities or self-help groups “from

below.” It is consequently unsurprising that a man with albinism whom I met in rural Ilula ward knew all the other people with albinism who lived nearby and within the entire ward. When I asked him why this was so, he replied: “I met them many times in the office of Kilolo district or when Sista Laurentina Bukombe distributed sunscreens and checked our skin in Ilula Mwaya.”

Public meetings, humanitarian actions and national media debates on the killings of people with albinism have thus strengthened the group identity of people with albinism themselves. Another strong catalyst for the creation of a common identity has been the reference to human rights: “We must help each other,” stated a woman with albinism when she referred to both the misperceptions of others about people with albinism as well as the poor employment prospects of individuals with albinism in the job market. Furthermore, this sense of a group identity and solidarity is sustained by the fact that people with albinism have been depicted by the international and national media as being exposed to attack in the north-western region of the country. It is also fostered by NGO campaigns that have promoted national gatherings, such as National Albinism Day. Finally, such a group identity has been cultivated by joint critical discourses towards the Tanzanian national government, which has been accused of failing to take action to stop the atrocities against people with albinism and of not taking care of its citizens with albinism.

Through this formation of a group identity, people with albinism aim to achieve the recognition of their rights as human beings and their full inclusion within Tanzanian society. The representational strategies used by NGOs and the media are now increasingly also portraying the strength and struggles of people with albinism to gain control over their own lives and overcome the discrimination against them. One instance of this is the film [“In the Shadow of the Sun” \(2012\)](#), co-produced by the BBC. Through the compelling stories of two people – Josephat Torner, the TAS communication and relations officer, and Vedastus Chinese Zangule, a 14-year-old boy with albinism – the documentary narrates how people with albinism can overcome discrimination by (re-)claiming control over their lives. Apart from the strong focus on their deservingness, poverty and victimhood, the message represents an alternative way in which the life experiences of people with albinism can be documented and spread by the media and NGOs.

Concluding Remarks: The Visual Politics of Representing the Lives of People with Albinism in Tanzania

From the mid-2000s onwards, the murders of people with albinism occurring in the north-western parts of Tanzania have attracted significant international attention. Since then, international and national NGOs, as well as governmental organizations and health centers in Tanzania, have implemented humanitarian projects and large-scale awareness campaigns to improve the life experiences of people with albinism and eliminate the aggressions towards and reduce the discrimination against them. All these actions have without doubt produced a shift in the perception of albinism in the Tanzanian population and have also reshaped the individual subjectivities of people with albinism themselves.

Furthermore, humanitarian interventions and awareness campaigns carried out by the national and international mass media and NGOs have also produced differences and hierarchies within local populations in terms of the appropriation of (bio)medical information and conceptions about albinism. Thus the socially more privileged and well educated people living in urban settings such as Iringa town in particular have been “touched” by the global flow of information more deeply, and have thereby assimilated the ideas and discourses spread by NGOs and the mass media regarding people with albinism. At the rural level, however, including the villages in which the people in the photos live, the encounters between global discourses and local ideas have triggered new identities and subjectivities in which new (bio)medical explanations, human rights claims, “traditional” perceptions and moral-religious ideas about the congenital condition have become intertwined. Thus while the majority of interviewees considered themselves to be persons with a disability, they simultaneously explained that albinism was “God’s plan,” which was said to manifest itself as a lack of vitamins or iron in the blood. They therefore shaped and reshaped new identities that were, in part, composed of the global flow of information and campaigning on their behalf. In this regard, people with albinism built on discourses of deservingness and victimhood when performing their identities in the context of NGOs. Furthermore, they developed a strong group identity based on the will to fight for their rights and reduce stigma in the country.

Comparing my work as an NGO staff member with my subsequent research fieldwork as an anthropologist highlights the way in which people with albinism, their relatives and community members enacted diverse ideas about the condition depending on whether they were confronted with one or the other of my two “public identities.” Therefore, an analysis of my positionality as a researcher (which I also held as an NGO staff member, though in a different way) unveils the shifting politics of (self-)representation in the locality of my study. In particular, the photos shown below (photos 9, 10) highlight the visual politics of how certain images of people with albinism circulate in the local and global media – sometimes there is an almost excessive number of photos of people with albinism and too much image representation of them in general – as well as the criteria that are applied by many NGOs when selecting the pictures to use to advertise their work.

In order to illustrate this point, I make use of two almost identical photos. The image in photo 9 illustrates a child with albinism being helped to put on a new pair of sunglasses provided by Tulime Onlus. Photo 10 depicts the same scene but from a different point of view. This time the child is wearing the sunglasses and her head is covered by a straw hat. Two volunteers, one Italian and one Tanzanian, and the TAS responsible for Kilolo district sit in front of her. Behind her, her grandmother and little brother sit on the ground in front of the house, while in the foreground a man from the village stands looking over the scene.

Apart from the actors and the environment shown in the pictures, the main difference between the two photos is the perspective from which both have been photographed. Photo 9, together with others in this essay (e.g. photo 8), might belong to the type of image production used by the media and NGOs: these photos present individuals with albinism in largely compassionate terms, emphasizing how they are in need of humanitarian aid or displaying the moment when

they are provided with it. The second photo, n. 10, reveals, on the contrary, the political and social context of the strategies put to use by humanitarian organizations (Fassin 2011), as well as the intertwinement between the individual life experiences of people with albinism at the local level (a life not so much different from other children's ones at rural as well as urban level) and the flow of images and information that circulate globally that mainly show both people with albinism encounter with NGO workers (e.g. those to who they can direct their claims for help) or those having the congenital condition as poorer than the average population without albinism. In this regard, the two pictures display the different types of visual politics that are at work in the production of "truth" about the life circumstances of people with albinism in Tanzania. They also hint to the way in which people with albinism and their families and communities struggle to (re)define their lives in the wake of global media and humanitarian attention and the risks and challenges they are exposed to in their everyday lives.

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Author

Giorgio Brocco is a PhD candidate at the Freie Universität Berlin. His doctoral research entitled "*Zeruzeru and Diverse Shades of Difference: A Study of People with Albinism in Kilolo District, Tanzania*" examines the life situations and everyday experiences of people with albinism in Tanzania. The main goal of the study is pursued through an investigation that deals with the social, political and moral discourses and ideas about albinism in Tanzania, as they are articulated by diverse actors between local and global settings. Since 2012, Giorgio Brocco has also worked for the NGO Tulime Onlus.

Footnotes

[1] The words in brackets are the original Kiswahili terms.

[2] All the names in the article are pseudonyms except the names of public persons.

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