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(Un)Categorizing Albinism

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By Giorgio Brocco

“Everything started with a little spot in the head, right up [by] my right ear! I don’t even remember the precise day or week I discovered it. Instead, I remember that it still hurts and I have a persistent headache!” Fadhili said with a feeble voice brightened by a soft smile. As our discussion of his health continued, he kept caressing his head, covered by a black wool cap, near the surface affected by the cutaneous cancer.

I encountered Fadhili,^[1] a rural farmer with albinism in March 2012, after we were put in touch by the district branch of the Tanzania Albinism Society (TAS), the national organization for people with albinism in the country. During a previous census of people with albinism carried out by the district state office throughout the Kilolo district (in the Iringa region of south-central Tanzania), the TAS representative became acquainted with Fadhili personally, although he was already known to TAS because his name had been given to the TAS by his village chairperson [*mwenyekiti*]; as such, the Tanzanian organization had already listed his name among the persons with albinism living in the district. Since Fadhili had never taken part in TAS meeting before, he was surprised to have been contacted by the district civil servants and members of TAS on that occasion. As time went by, Fadhili had remained in contact with the TAS representative and asked him for economic support when the pain had become unbearable.



The image is of a brochure providing biomedical information about the genetic inheritance of albinism. A particularly prominent sentence on the brochure is, "The disability of the skin all over the world: We are not alone. (*Ulemavu wa ngozi duniani kote: Hatupo peke yetu.*)" This sentence is framed by images of persons with albinism from all around the world. Produced and distributed by the Canadian NGO Under The Same Sun (UTSS), the poster was hung up on the wall of one woman's house in the Kilolo district. Giorgio Brocco 2013

On the recommendation of a TAS member, I decided to visit Fadhili and his family in a small village called Ukwega. The day after I met him, Fadhili was brought to the local regional hospital where a physician stated that he had a "tremendous melanoma with possible metastasis." The devastating news left Fadhili and his wife, Anjela, dazed. In two earlier community presentations organized by TAS and civil servants at the Kilolo district office, they had heard about cancer, but could not imagine that the pathology was presenting itself in their lives. Before that discovery, Fadhili, as Anjela told me, had identified himself as a man with a light(er)/white skin [*mtu mwenye ngozi nyeupe*] or a "zeruzeru." The latter is a Swahili term, the etymology of which is unclear, that has been translated as "ghost" in the course of the humanitarian interventions. Both words refer to the "whiteness" of the skin of people with albinism (see Brocco 2015).

At no point had Fadhili anticipated having cancer. "This wound is just the complication of an infection due to a previous sunburn," or so went the quick diagnosis that Fadhili received from another medical doctor in 2011.

No more information was given, just a few medications that he could not afford to buy. As a result, Fadhili resolved to only consult a local healer to reduce the pain caused by the disease. *Docta* Amani Mdele was a healer of Christian faith who resided in a nearby small town, attracting patients from the entire area. Although the healer was providing Fadhili with various types of medicines—“traditional”/local medicine (*dawa ya kienyeji*), natural medicine (*dawa ya asilia*), and healing remedies obtained from plants, trees and roots, from the fields (*dawa ya miti shamba*)—he also suggested that Fadhili use modern medicine (*dawa ya kisasa*) from the hospital to improve his health.[\[2\]](#)

After the diagnosis in 2012, skin cancer suddenly emerged as a meaningful component of a new biomedical etiology in Fadhili’s life. In this way, moreover, Fadhili’s story reflects the wider, and often literal, materialization of categories of “albinism” and “disability of the skin” in contemporary Tanzania. Together with low vision and lack of melanin in the body, skin cancer was already associated with albinism in (inter)national media and political debates. Throughout Tanzania, a handful of other health facilities and hospitals were involved in spreading guidelines for skin cancer prevention, offering sunscreen lotions, and carrying out surgical operations and chemotherapy for treating cancerous lesions, all with state and international humanitarian support.

At the same time, over the last decade, a series of violent assaults and murders of people with albinism have provoked widespread media attention. Both reporting and rumors about the illicit trade and use of body parts organized by traditional healers have galvanized burgeoning NGO interventions. Meanwhile, media representations and popular performances about “albinicide” have imbued the category of albinism with humanitarian urgency. These efforts have purported to improve biomedical and human rights understandings of albinism in Tanzania, and they aim to reduce the social marginalization of individuals with albinism and enhance their economic situations. Such efforts also seek to extend state protection for adults and children with albinism, while eradicating “traditional” healing practices and stigmatizing ideas in society (Baker et al. 2009).

For Fadhili, these larger processes unfolded on a personal level over the year that he spent in Iringa, during a first recovery from cancer, and the Ocean Road Cancer Institute (ORCI) in Dar es Salaam thereafter. Both his medical treatments and his travels were partly supported by an Italian NGO, a Tanzanian CBO (Community Based Organization), and one of Fadhili’s relatives in Dar es Salaam. After about a year of treatments, Fadhili, who was 44 years old at the time, passed away. His body was transported back from the Dar es Salaam cancer institute, where he died, and buried in his small hometown.

After Fadhili's death, I recalled a moment from what, at the time, had seemed like his recovery in Dar es Salaam. Sitting on a crowded bench outside the oncology department, Anjela and I were waiting to speak with a physician to get more information about her husband's first round of chemotherapy. At one point in our conversation, Anjela asserted: "I suggested that he see a doctor in Kilolo [the district capital town] many times. If it had been solely up to him, he would have continued to take *dawa ya kienyeji* [local medicine] to spare the little money that we have!" She looked tired from the waiting, and she spoke with a mixture of bewilderment and resignation. Then, she suddenly added: "I figured out that persons with light/white skin like him could get these problems [*matatizo*]!" The fact that Anjela neither identified her husband as a person with a "disability of the skin" nor used the NGO-sanctioned term "man with albinism" surprised me. Anjela firmly categorized Fadhili and others with similar phenotypical appearances as individuals with a white/light(er) skin. The words uttered by Fadhili's wife echoed the many times in 2012 I heard people in Kilolo district define individuals with albinism in similar way, as *zeruzeru*.

The discovery of Fadhili's skin cancer, his death and Anjela's arguments reveal multiple, entangled and at-times competing socio-historically layers that shape understandings and experiences of albinism in Tanzania today. These brief sketches of Fadhili's life relating to his interactions with NGOs, biomedicine, and other kinds of healing systems reveal paradigmatic instances of the multiple realities around this contested and never-neutral category of albinism (Saffitz 2018). Fadhili's story partakes in a form of mutual "enfleshment" (Povinelli 2011) with other life trajectories defined by albinism that I followed over 19 months of fieldwork in Tanzania, spanning 2012 to 2015. Musical performances, religious conceptions, political experiences and activist involvements in the media and the humanitarian sector all shape how people with albinism in Tanzania refer to their condition.

On the ground, political and media attention to albinism has created something less than a biosociality, but nonetheless has triggered the emergence of national and international networks based on similar bodily features, shared social issues and convergent political rights' claims. This happened in Fadhili's case: he had some sporadic contacts with other persons with albinism through NGOs and sought biomedical treatments. Nonetheless he also believed that the condition was due to a plan of God (*mpango wa Mungu*) and repeatedly saw a local healer in Ukwega. Fadhili's economic vulnerability and lack of access to broader networks of humanitarian help in fact led him to seek "local" etiological and diagnostic systems to reduce the pain caused by the cancer. His experience with albinism underlines the discrepancies between a biomedical conception of albinism, spread by media and humanitarian actions, and an individual

understanding of the condition in which religious-moral ideas are intertwined with biomedical etiologies and local healing practices.

The end of violence and stigma, free health assistance from the Tanzanian state, educational support and the constitution of a more inclusive job market: these are some of the rights advanced by national and international activist movements on behalf of children and adults with albinism in Tanzania and other African nation-states. The contested definition of albinism as a disability represents one material way through which people with albinism can publicly advance these rights as a group with specific needs as well as one category of physical impairment.

Although Fadhili and his wife Anjela never referred to albinism as a disability, his tragic encounter with cancer illustrates one of the typical examples today used by media and activist movements to make claims for the social rights of people with the condition. Along these lines, the categorization of albinism as a physical impairment (*ulemavu wa ngozi* – disability of the skin) is intended to emphasize the social and individual issues that follow from having low vision and depigmented/lighter skin. The TAS has been registered as a Disabled's People Organization (DPO) since 1980, under the government of Nyerere. At the same time, some international NGOs understood albinism as a genetic condition but not as a disability at the beginning of the humanitarian turmoil in reaction to violence against people with the condition.

The meaning of “albinism” in Fadhili’s life thus stems from many factors such as rights-based activism, humanitarian actions, religious conceptions and subjective understandings of the condition. His life and his tragic death highlight that the emergence of multiple discourses and practices about albinism, symbolic and material axes through which persons like Fadhili and Anjela conceive the condition nowadays.

[1] All the names used here are pseudonyms.

[2] The distinction between local/traditional and natural medicine is both political and historical. The Tanzanian government has encouraged the development of healing practices that entail the exclusive use of plants remedies. In an effort to meet national and international development goals, the political authorities have also aimed to facilitate the integration of “modern” medical systems and “traditional” therapeutic practices. Healing practices involving the use of both plant remedies and supernatural entities are categorized as “*kienyeji*.” At the level of everyday interactions, however, the distinction between local/traditional and natural medicine is not fixed. See, e.g., Langwick 2011. On the various entanglements of “traditional” and “modern/biomedical” healing practices, see, e.g., Marsland 2007, Langwick 2008 and Nichols-Belo

2018.

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