AM

50 / dicembre 2020

RIVISTA DELLA SOCIETÀ ITALIANA DI ANTROPOLOGIA MEDICA
FONDATA DA TULLIO SEPPILLI

Fondazione Angelo Celli per una Cultura della Salute - Perugia

In copertina

Sfilata per le strade di Mekelle (Tigray, Etiopia), in occasione della *Giornata internazionale delle persone con disabilità*. Foto di campo di Virginia De Silva (dicembre 2014).

Il logo della Società italiana di antropologia medica, qui riprodotto, costituisce la elaborazione grafica di un ideogramma cinese molto antico che ha via via assunto il significato di "longevità", risultato di una vita consapevolmente condotta lungo una ininterrotta via di armonia e di equilibrio.

AM

Rivista della Società italiana di antropologia medica
Journal of the Italian Society for Medical Anthropology

Fondata da / Founded by
Tullio Seppilli

Biannual open access peer-reviewed online Journal

50
dicembre 2020
December 2020

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AM. Rivista della Società italiana di antropologia medica fondata da Tullio Seppilli è una testata semestrale della Fondazione Angelo Celli per una cultura della salute (Perugia).

AM
Rivista della Società italiana di antropologia medica
fondata da Tullio Seppilli
Journal of the Italian Society for Medical Anthropology
Founded by Tullio Seppilli

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Editoriale

AM 50: un nuovo inizio

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Care Lettrici e Cari Lettori,

presentiamo qui il numero 50 di AM, il secondo della nuova veste digitale. La rivista è in corso di verifica e vi saranno ulteriori cambiamenti: la transizione non finisce, ma ci siamo.

Siamo a “un nuovo inizio” e tutto dipende da noi: abbiamo recuperato gli enormi ritardi di AM già con i tre volumi dal 2016 al 2019: 41-42 del 2016, 43-46 del 2017-2018 (firmati da Tullio Seppilli, in quanto egli li aveva già programmati e precedentemente messi in opera) e 47-48 del 2019 (che ricordo essere l’ultimo volume cartaceo).

Nel 2020 abbiamo raggiunto l’obiettivo più ambìto: rendere tutta la collezione di AM dal 1996 a tuttora liberamente disponibile in internet come Archivio, contestualmente all’uscita del numero 49, il primo di AM in edizione digitale.

Come già sapete la nostra rivista prosegue le pubblicazioni *online* con due numeri l’anno *open access* che vedranno un’uscita cadenzata nei mesi di giugno e dicembre con una programmazione triennale.

Grazie a tutte e a tutti per l’accoglienza gioiosa che ci avete riservato per questo traguardo: innanzitutto a coloro che hanno contribuito a realizzarlo, cioè alle colleghe e ai colleghi del Comitato di redazione della versione cartacea di AM, senza le/i quali non avremmo mai potuto ottenere questi risultati; a Cristina Papa e ad Alessandro Lupo, da lungo tempo compagni di lavoro solerti e leali, che hanno accettato di presiedere l’una la Fondazione Angelo Celli per una Cultura della Salute e l’altro la Società italiana di antropologia medica (Siam) con uno spirito di servizio tenace, competente e unitario; a tutte e a tutti i membri del Comitato scientifico, che contribuiscono a illuminare la nostra rivista, organo nazionale della Siam; ai colleghi e alle colleghe del Consiglio direttivo della Siam, che hanno accettato di far parte del nuovo Comitato di redazione dell'edizione digitale e, *last but not least*, a tutti e a tutte voi, lettori e lettrici, che seguendo la rivista e/o contribuendo a essa, siete il principale riferimento di AM.

«Tullio Seppilli sarebbe stato contento». È questa la frase che mi è più di tutte entrata nel cuore allorché abbiamo raggiunto la meta di portare AM su OJS. La nostra rivista ora appare sulla piattaforma dell'Università di Perugia e da qui può raggiungere tutti gli altri Paesi. Anche nella programmazione dobbiamo un po' ripensare il *target*. Abbiamo il compito di rappresentare all'esterno l'identità dell'antropologia medica italiana e grazie all'impegno di tutt* ce la faremo. Pur rimanendo un periodico italiano, guardiamo a un pubblico internazionale, composto dalle colleghe e dai colleghi di tutto il mondo (com'è noto, accettiamo saggi e contributi in diverse lingue: italiano, francese, spagnolo, inglese e portoghese), che sanno guardare all'ampliamento che la disciplina specialistica dell'antropologia medica sta vivendo nel momento contemporaneo a livello planetario.

Con l'uscita del primo numero digitale abbiamo avuto riconoscimenti internazionali importanti, da parte di colleghe e colleghi di prestigio; sono fioccate E-mail di congratulazioni da più parti, dirette a me solo perché in questo frangente sono il direttore di questo periodico, a testimonianza della grandiosa capacità di Tullio Seppilli di costruire reti mondiali nel campo dell'antropologia medica internazionale.

In effetti tutto quello che programmiamo, silenziosamente o loquacemente, lo facciamo nel nome di Seppilli. Certo con autonomia e responsabilità, ma non a caso portiamo avanti una rivista con iniziative nelle quali la sua presenza è molto evidente. E lo mostra questo numero 50, sia nella sezione monografica sia in quella generale.

Ospitiamo nella sezione monografica una selezione dei contributi più pertinenti per l'antropologia medica presentati, selezionati e riscritti per l'occasione da alcuni dei partecipanti alle due giornate di studio su *Antropologia medica & Disabilità* che organizzammo nell'ateneo perugino l'8 e il 9 novembre del 2019. Si trattò dell'esito laboratoriale collettivo, a opera di un gruppo che fondammo proprio raccogliendo la richiesta di coloro che furono i primi tre aderenti: Virginia De Silva, Fabrizio Loce-Mandes e Francesca Pistone, studiosi indipendenti che hanno svolto il loro dottorato di ricerca lavorando etnograficamente sul tema della disabilità e che al contempo hanno preso parte a diverse sessioni del 2° Convegno nazionale della Siam *«Un'antropologia per capire, per agire, per impegnarsi». La lezione di*

Tullio Seppilli, svoltosi all'Università di Perugia, il 14-16 giugno 2018, al quale abbiamo dedicato l'ultimo volume cartaceo di AM (ottobre 2019 / 47-48, con una selezione degli interventi tenuti alla sessione coordinata da Massimiliano Minelli e da me) e il primo numero digitale della rivista (giugno 2020 / 49, con le relazioni plenarie).

Insieme a Massimiliano Minelli, Andrea F. Ravenda e Nicoletta Sciarrino, dopo il convegno del 2018, abbiamo contribuito a configurare un gruppo di lavoro denominandolo AM&D. Una *équipe* che, accanto alla *Call* di quel seminario, ha scritto un documento comune, una sorta di *manifesto*, che qui di seguito riproduciamo per intero, anche perché da esso si evince il debito scientifico e politico che dobbiamo alla lezione di Tullio Seppilli:

> Il gruppo AM&D (Antropologia Medica e Disabilità) nasce dall'incontro di ricercatrici e ricercatori intorno alla tematica della disabilità, a seguito del II Convegno nazionale della Società italiana di antropologia medica (Siam) tenutosi a Perugia nel giugno del 2018 *«Un'antropologia per capire, per agire, per impegnarsi». La lezione di Tullio Seppilli*. Attraverso lo studio e la ricerca, il gruppo intende valorizzare lo spazio di azione della teoria e della pratica antropologica all'interno del campo della disabilità. Le prospettive di antropologia medica che perseguiamo non hanno l'intento di ri-medicalizzare o antropo-medicalizzare la questione della disabilità, ma evocano un'antropologia critico-politica del corpo, dialogica e sperimentale, incentrata sui processi di incorporazione, di ben-essere e, quindi, di salute. La disabilità emerge come un "campo", inteso sia come spazio di riconoscimento reciproco tra gli attori sociali, sia come terreno di contesa regolato da rapporti di forza. Ne risulta evidenziata la natura innaturale e storicamente determinata della disabilità. La pratica etnografica permette di connettere le esperienze più intime di condizioni "disabilitanti" con i discorsi pubblici e istituzionali; di analizzare le ricadute locali di processi globali, come la Convenzione delle Nazioni Unite sui Diritti delle Persone con Disabilità e i documenti delle agenzie internazionali; di mettere in discussione le categorie di "vulnerabilità", "marginalità" e soprattutto "funzionamento" e "abilità". I lavori scientifici del gruppo, nella loro pluralità, sono uniti dal filo rosso di uno sguardo critico e de-essenzializzante, attento alle politiche di dis-abilitazione di alcune categorie di attori sociali e a quelle di riconoscimento, al disvelamento dell'abilismo incorporato, alle retoriche di *empowerment*, di autonomia e di indipendenza coniugate in maniera specifica all'interno dei sistemi neoliberali. Si va dallo studio dei dispositivi dello sviluppo a quello delle pratiche di cittadinanza attiva, dalle esperienze del corpo nella sua continua relazione con il contesto in cui si trova alle infinite possibilità aperte da pratiche insorgenti. Nell'ottica qui delineata il gruppo AM&D si impegna in «attività di ricerca con finalità operative tese a fondare processi di consapevolezza e di liberazione» (Tullio Seppilli). Il gruppo

> AM&D è composto da: Virginia De Silva (coordinatrice) / Fabrizio Loce-Mandes / Massimiliano Minelli / Francesca Pistone / Giovanni Pizza / Andrea F. Ravenda / Nicoletta Sciarrino.

Grazie a Virginia De Silva che ha accettato di coordinare il gruppo AM&D e di curare i due volumi che costituiscono in termini di pubblicazioni una selezione di qualità degli esiti di quel seminario di due giornate: la sezione monografica di AM e un numero dedicato a questo tema dalla rivista napoletana di *Disability studies* "Minority Reports". AM e MR si sono uniti in una sfida co-disciplinare: spingere l'antropologia medica e i *disability studies* a un confronto necessario, argomento sviluppato da De Silva nelle introduzioni a entrambi i monografici e più volte ripreso nei saggi successivi da lei presentati.

Inoltre, nella sezione generale, accogliamo scritti eterogenei, che vanno dalle analisi etnografiche sulla riduzione del danno, alla collaborazione transdisciplinare con esponenti della ricerca biomedica fino alla riflessione filosofico-antropologica sulla fondazione da parte di Ernesto de Martino del rapporto fra antropologia e arte.

Anche se in un'ottica del tutto nuova, riprenderemo progressivamente a pubblicare l'insieme delle rubriche che, nella loro ricchezza, caratterizzarono i primi anni della rivista, ispirandoci all'*Osservatorio*, ideato da Seppilli. Cominciamo in questo numero a ripristinare i *Lavori in corso*.

Infine, puntiamo molto sulle recensioni, un genere di scrittura non sempre difeso in Italia. Per noi esse costituiscono una parte indispensabile di AM, perché danno conto di volumi importanti, del presente, soprattutto, ma anche del passato, che a livello mondiale sviluppano la ricerca antropologico-medica orientandola in direzioni plurali.

È al termine di un anno particolarmente complesso che licenziamo questo numero 50 di AM, chiedendovi di continuare a seguirci come già state generosamente facendo.

Siamo ben consapevoli della mole eccezionale di questo particolare fascicolo, che, pure essendo singolo, si avvicina ad alcuni volumi doppi della collezione. Tale ampiezza non si ripeterà in futuro, ma ora essa sta a rappresentare il nostro omaggio alla memoria.

Grazie, auguri e saluti fraterni a tutte e a tutti coloro che in modi diversi sostengono la nostra amata AM.

AM
Rivista della Società italiana di antropologia medica / 50, dicembre 2020, pp. 145-169

Entangled Narratives

Encountering Political Subjectivities of People with Albinism in Tanzania

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Abstract

Entangled Narratives. Encountering Political Subjectivities of People with Albinism in Tanzania

After the spread of media news about the attacks against people with albinism in Tanzania, humanitarian activism and media debates have accelerated the emergence and production of discourses about people with the condition in the country. Victimhood, deservingness and equivalence of albinism with disability represent three of the most recurring media and humanitarian narratives. Based on data collected over 19 months of fieldwork in Tanzania, the present article explores how discourses and ideas about albinism have circulated among and been reformulated by people with albinism to deconstruct shared conceptions of normalcy and affirm their agency in the Tanzanian public arena. The ethnographic material shows in which multiple ways the intertwinement of global actions and everyday practices related to albinism have strengthened already-existing political subjectivities, (re)shaped political claims, and articulated ideas of (dis)belonging.

Keywords: albinism, political subjectivity, humanitarianism, belonging, Tanzania

Introduction

According to the biomedical literature, albinism is a genetic condition due to a deficit in melanin production of the skin, hair and eyes. Major health issues for people with albinism in many African countries are lifelong sun-induced skin damage, high insurgence of skin cancer, and impaired eyesight (e.g. involuntary nystagmus, photophobia, poor depth perception, strabismus, poor visual acuity and refractive errors). The presence of these medical issues can affect the physical and mental health and wellbeing of people with albinism (Lund 2001; Kromberg, Manga 2018). 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 approximately 0.04 percent of the total population of 44,928,923 (*ibidem*).

Since approximately 2007, 170 attacks against and 76 murders of people with albinism have been recorded in Tanzania and neighboring countries (Under the same sun 2017). Violence against people with albinism predominantly took place in Tanzania's northwestern regions, mainly on the shore of Lake Victoria (Schüle 2013). International and national newspaper reports and radio/TV coverage indicated that male gangs of assailants have mostly been responsible for attacks against people with albinism. According to these media reports, victims were subjected to butchering assaults and dismembered with machetes. Their organs, bones, and body parts were collected and sold to traditional healers or "witchdoctors" (Bryceson, Jonsson, Sherrington 2010; Burke, Kaijage, John-Langba 2014). The "rumorscapes" (White 2000) about the trade in body parts of people with albinism have fueled the commodification of their limbs from which to obtain "magic" amulets to enhance wealth and luck (Bryceson, Jonsson, Sherrington 2010; Schüle 2013). Due to their physical appearance and stigmatizing ideas about the condition within the society, people with albinism have become the target of violence and attacks. Besides this explanation, some research argue that the motivation for the assaults can be found in the unpredictable neo-liberal context of Tanzania's recent fishing and mining industries boom that has contributed to the emergence of the "occult" market demand for body parts among crowds of migrant workers living in conditions of economic deprivation and social vulnerability (Bryceson, Jonsson, Sherrington 2010; Schüle 2013; Kromberg, Manga 2018; Franklin *et al.* 2018).

Most of the media reports have assigned blame to so called "traditional superstitions" and "witchdoctors," overlooking the social and political reasons behind the violence against people with albinism (Ntetema 2008; Alum *et al.* 2009; Burke, Kaijage, John-Langba 2014). In the wake of the news about such attacks, international and national Ngos, humanitarian bodies, broadcasting media, civil society and national and international scholars have begun to mobilize and campaign on behalf of people with albinism who are said to live in conditions of social deprivation and stigma. Media reports, political categorizations of disability and albinism, and humanitarian and (bio)medical conceptions about the condition, understood as a visual and physical impairment, have produced several narratives. Victimhood, deservingness, and the equivalence of albinism with disability are three of the most recurrent media and humanitarian discourses.

When describing their own life conditions, some of the Tanzanian persons with albinism themselves relate to and mobilize various versions of these discourses. In fact, persons with albinism variously appropriate, reformulate and counter these various narratives to advance already-existing political claims, improve their socioeconomic status in the society, and express forms of identification and belonging from their diverse social positions (Yuval-Davis 2006, 2007). Although such discourses are articulated by people with albinism in various ways, they constitute interlinked subject positions from where these persons make political claims, express practices of social inclusion, and manifest longing and desire of belonging (Krause, Schramm 2011). Reformulated versions of these official narratives therefore make up the political subjectivities of people with albinism and display dynamics and politics of (dis)belonging during public events and in relation to state authorities, such as the *International Albinism Awareness Day* (Iaad).

Based on ethnographic materials collected over nineteen months (August-November 2012, November 2013-May 2014 and February-September 2015) of fieldwork in Tanzania,[1] the paper explores the formation of multiple political claims and subjective positions among people with albinism. This includes ideas, discourses, and practices about albinism in relation and in dialectical contraposition to the aforementioned narratives (e.g. victimhood, deservingness and equivalence of albinism with disability) generated and spread by networks of institutional arrangements constituted by: Ngos, national activism, humanitarian agencies, and media debates. In the first sections of the paper, I introduce the concept of political subjectivities, previous information on albinism, and the humanitarian works carried out by the most relevant (inter)national organizations in Tanzania. Consequently, I discuss the selected discourses about the condition and relate them to the ethnographic material collected during fieldwork. Through the analysis of five case studies, I argue that global actions, media reports, and rumors enhance the emergence of already-existing political claims and advance the enactment of political subjectivities by people with albinism in Tanzania. As the ethnographic material shows, international narratives and ideas about the condition have triggered the development of social relationships and notions of citizenship around common biological conditions associated with albinism.[2] People with albinism variously adhere to, criticize, enact or refuse official narratives and practices of albinism and tend to formulate their own ideas of group belonging/dis-belonging which constitute their multiple political subjectivities.

Multiple Political Subjectivities and Their Articulation

The concept of political subjectivities helps to explain the entanglement of global and local conceptions of albinism, the (re)production of subjectivities in "times of crisis" (Mbembe, Roitman 1995) and the resulting formation of new imagined forms of group belonging to society based on the interplay of biologies, health entitlements, and citizenship rights (Biehl 2007; Nguyen 2010). This analytical concept highlights how people with albinism employ practices and discourses to redefine widespread social ideas of normalcy in Tanzania by redefying social positioning related to various biological conditions. Political subjectivities highlight the multiple ways in which a single individual or group of people try to gain a political position and be recognized by political authorities and other members of the society. Furthermore, the analytical term underlines the subjective political and affective dimensions within domains of group belonging informed by social imaginaries (Taylor 2002) and the politics of citizenship (Krause, Schramm 2011).

For albinism in Tanzania, the political subjectivities allow for an inquiry into how people make political claims for their condition through the production of certain practices and discourses. As they are informed by the intertwining of information flow, spiritual/religious ideas and discourses within global-local social "spaces of heterogeneity" (Howarth 2006).

To analyze the political subjectivities in people with albinism, some of the selected discourses/official narratives (e.g. victimhood, deservingness and albinism as disability) produced by global actors are introduced and discussed in depth. Victimhood refers to a collective identity derived from the attacks and health issues related to albinism (Jacobi 2014). Through narratives of victimhood, society is dichotomously divided into victims (people with albinism) and media-supposed perpetrators (traditional healers, gangs of men hired by them, politicians and businessmen). The corporeality and corporeal evidences (Guglielmo 2015) of the victims with their "non-normative" biologies become the visible signs. Therefore, victimhood and practices of deservingness allow people with albinism to transform narratives about attacks and skin diseases into a political capital (Yildiz, Verkuyten 2011) to address their right to equal health and societal inclusion. On the same level, the various narratives of albinism as a disability are powerful means by which a strong sense of group belonging in people with albinism emerge. As these heterogeneous narratives materialize, albinism is conceived of as a physical impairment due to ophthalmological issues and lack of melanin in the skin. This is in addition to albinism as a disabling condition in which stigma and environmental issues play a great role by obstructing their full social realization in a "disabling" society (Thomas 2004; Ingstad, Whyte 2007; Goodley 2013).

(Re)shaped versions of these discourses catalyze political subjectivities of people with albinism through modes of belonging (Rutherford 2008) and experiential dimensions of subjectivity (Biehl, Good, Kleinman 2007; Blackman *et al.* 2008). Social practices and routinized discourses of belonging by which people with albinism make claims for resources and rights are in fact composed of three levels of identification (Yuval-Davis 2006, 2007): social, self and political. These three levels of belonging are produced by the interrelationships between the local understanding of albinism and the global flow of information and discourses on the condition. Ngo actions and media campaigns on issues related to albinism in Tanzania (re)locate identities and differences within new political boundaries and social classifications (Vigh 2006). The modes of belonging for people with albinism are also influenced and informed by emotional attachments due to the assaults and attacks against people with albinism (Kannabiran *et al.* 2006) and/or autobiographical narratives related to relatives with the condition within a family (Brunner 2004; Yuval-Davis 2006). The productive intersections of individuals' understanding, official narratives, political capital and various forms of group belonging prompt the production of multiple political subjectivities in people with albinism as shown in the ethnographic materials presented next.

Background: Framing Albinism in Tanzania and Beyond

Previous literature on albinism in the African continent and other world settings mainly describes people with the condition as victims of stigma and social marginalization due to religious and moral ideas linked to their distinct physical features and the secondary health issues associated to albinism (Carnegie 1996; Blankenberg 2000; Wan 2003; Baker *et al.* 2010). Even though generally considered as "God's will" (Braathen, Ingstad 2006; Baker *et al.* 2010), albinism is described in many researches as caused by moral misdeeds and maternal infidelity (Blankenberg 2000; Djatou 2009). According to the majority of scholars working on this topic, adults and children with albinism are affected by social rejection and inequalities (Reimer-Kirkham *et al.* 2019). Their lives are depicted as characterized by situational and cultural "ambiguity" (Machoko 2013). For instance, stigma from skin-color difference and visual impairments may lead to social exclusion of children and adults with albinism in public places and schools (Lund 2001; Gaigher, Lund, Makuya 2002). On the other hand, people with albinism can experience acceptance and inclusion within their networks of family relatedness (Braathen, Ingstad 2006) and in self-help groups and local organizations (Chelala 2007). With the production of new political identities for people with albinism as disabled individuals, adults and children develop diverging generational discourses and experiences of their conditions (Nyamu 2020). In order to reduce stigma and improve their social life, many scholarly works describe the adoption of human rights policies (Nkrumah 2018) and the implementation of health facilities for skin cancer treatments (Franklin *et al.* 2018) in various African countries.

In Tanzania, perceptions of albinism have been influenced to various extent by the actions and awareness campaigns conducted by NGOs and humanitarian institutions (Brocco 2015) as well as by the global spectacularization of the "albinotic body" in the media and fashion industries (Hohl, Krings 2019). As shown in previous research conducted in Tanzania (Brocco 2015), the entanglement of religious/spiritual explanations, human rights concepts, (bio)medical categorizations and existing stigmatizing opinions of albinism are visible in current labeling and terms. Even despite the presence of such heterogeneous etiologies, albinism is widely considered to be a condition brought about by God, which manifests as a lack of vitamins or minerals (*madini*[3]) in the blood. Furthermore, the condition is sometimes described to be the manifestation of a curse (*laana*) attached to the family because of the past misdeeds of one member (Brocco 2015). Besides these religious/moral explanations for albinism, biomedical information is equally widespread.

Stigmatizing attitudes towards and the individual moral concerns of people with albinism depend on family ties, economic situations, social status, levels of education, political involvement and religious-moral thoughts (Brocco 2016). On the one hand, albinism enhances vulnerability and affects a person's social status. On the other hand, religious discourses, humanitarian narratives (i.e., the self-conception of albinism as a 'normal condition' and/or a disability) and biomedical conceptions are means by which people with albinism in Tanzania try to develop a self-identity imbued with the "positive" values of their condition, promote self-empowerment and gain public recognition (Brocco 2016).

International Activism and the Production of Narratives and Discourses

Following the intense and far-reaching attention to the attacks and assaults against people with albinism, many African national governments, (inter)national organizations, and Ngos have implemented human rights programs in Tanzania and other countries to defend and support people with albinism and create awareness campaigns on their behalf (Engstrad-Neacsu, Wynter 2009; Burke, Kaijage, John-Langba 2014; Nkrumah 2018). In the following, I briefly introduce the most significant (inter)national Ngos that have carried out humanitarian actions in Tanzania so far and the ways these actors and media reports have articulated the aforementioned discourses.

Under the same sun (Utss), a christian Ngo from Canada founded by Peter Ash in 2008 and operating in Tanzania since 2009, is 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 northwestern part of Tanzania. Aside from these activities, Utss provides young boys and girls with albinism with approximately 320 scholarships countrywide, allowing them to pursue their studies. The Tanzania albinism society (Tas) is the national organization that exclusively addresses (and is managed by) people with albinism in Tanzania. Every year, Tas organizes a *National Albinism Day* with support from the Tanzanian government and sponsorship of international donors. In 2015, this day became the United Nations-recognized *International Albinism Awareness Day*. Tas aims to conduct awareness campaigns on behalf of people with albinism, even though the content of its activities and financial resources depend largely on international donors and other related organizations, such as Utss. Finally, Standing voice is a UK based organization founded in 2013 by Harry Freeland, director of the documentary “In the Shadow of the Sun” (2012). Standing voice is a Ngo that addresses advocacy and health issues for people with the condition and its programs focus on low-vision care and skin cancer prevention.

Utss, Standing voice, the Tanzanian national government and Unicef (United nations children’s fund) all support the spread of mobile ophthalmological and dermatological clinics and skin cancer treatments. These medical activities mainly take place in the Kilimanjaro christian medical center (Kcmc) in Moshi, Tanzania. This referral hospital, founded in 1971 by the Good samaritan foundation, houses one of the most important Tanzanian health centers specializing in cancer and venero-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 is promoted by the International foundation for dermatology and associated with the Kilimanjaro christian medical college. The center conducts a program in collaboration with Utss called *Kilimanjaro Sun Care Cream*, supporting the needs of people with albinism and training them in sunscreen preparation (Hay 2013). An important part of the Rdtc is the Kilimanjaro sunscreen production unit (Kspu), a laboratory where a nationally manufactured sunscreen called "Kilisun" is produced and distributed.

All these national and international organizations are devoted to highlighting and addressing how people with albinism suffer from visual issues and skin cancer. Thus, while these attacks produce narratives of victimhood and human rights justice, health issues related to albinism create discourses of deservingness. For instance, a large number of media reports and (inter)national newspapers' articles use the words "rights," "justice" and "*haki*" (Swahili for both rights and justice) to address the rights to life, education, health services, work, freedom of movement and the political participation of people with albinism (Burke, Kaijage, John-Langba 2014: 126). Another example of such discourses spread by broadcasting media are the lyrics of Ras Six, a young Tanzanian bongo flava/reggae singer with albinism. In some of his song lyrics, the Tanzanian musician refers to the attacks against and killings of people with albinism claiming justice and equal social rights, while describing difficulties and health problems these persons encounter during life (Brocco 2020).

Another articulation of albinism in activist discourses is to categorize the condition as a disability[4] (Franklin *et al.* 2018), even despite this definition is not equally accepted by all Ngos working on albinism nor is it formally written into the "Tanzanian Disability Act" of 2010 and other international official documents, such as the "Human Rights Council Resolution on Attacks and Discrimination against Persons with Albinism" (Salewi 2011; Possi, Possi 2017). Some organizations (for instance Utss), governmental agencies and Tanzanian national institutions implicitly make the assumption that people with albinism should be considered as legally blind suffering from a disability of the skin (the previous Kiswahili translation for albinism has been "a disability of the skin" or *ulemavu wa ngozi*). On the other hand, there are other international charities, such as the National organization for albinism and hypopigmentation (Noah), that consider albinism as an independent genetic condition not comparable to any other physical and mental impairment. The Ngos that consider albinism as a disability conduct awareness campaigns in many rural areas in Tanzania with the message that people with albinism are as 'normal' as other people and should be included within society. One of the significant instance addressing and reformulating the equation of albinism with disability is the Utss's booklet entitled *Classifying Albinism: Transforming Perceptions and Ushering in Protection*. This document, presented to the advisory committee of the United Nations Human Rights Council in 2014, specifies that albinism can be categorized as a disability as a result of visual and skin impairments. Nonetheless, the equivalence of albinism with a disability is insufficient "to protect Pwa in light of the multiple and intersecting levels of discrimination they face as caused by the totality of their *albinistic* appearance, a critical aspect which is not 'impairment' per se" (Under the same sun 2014: 28).

"No one presents you nothing, you have to deserve it!": Reformulated Constellations of Deservingness and Victimhood

Victimhood refers to a temporally situated category derived from the attacks against and health issues related to albinism (Jacobi 2014; Jensen, Ronsbo 2014). Through narratives of victimhood, society is dichotomously divided into suffering victims (people with albinism) of violence and (media) alleged perpetrators (traditional healers, gangs of men hired by them, politicians and businessmen). The corporeality and corporeal evidences (Guglielmo 2015) of the victims with their "non-normative" biologies become the visible signs for these claims.

In conjunction with victimhood, discourses of deservingness are related to the ways people with albinism present themselves as "helpless sufferers" (Huschke 2014) in connection with news and humanitarian actions related to the assaults and the economic vulnerability in which some of these persons live. At an individual level, deservingness concerns the perceived moral feelings of being included in the society and being entitled to having equal rights and opportunities (Willen 2012). Victimhood and practices of deservingness allow people with albinism to transform official narratives into a political capital (Yildiz, Verkuyten 2011) to address their right to equal health and societal inclusion. Through the ethnographic material analyzed below, I underline how discourses of victimhood and deservingness are variously reformulated by the research participants with albinism and constitute their multiple subject positions in relation to their life trajectories.

Beatrice Kinalilo[5] was a 48-year-old woman, originally from the Manyara region where she completed her primary education. She met her future husband in the 1980s when he was an extension officer working for the government in Manyara region. Together they had five children. When her husband retired, they moved to the Iringa region, where her husband was from originally. Sometime later after the death of her husband, Beatrice was forced to sell one of the fields and started cultivating rented land in Image, a small conglomerate of houses near the villages of the Ilula ward along the paved road to Iringa.

The last time we met in Image, Beatrice expressed her desire to put herself forward as the new five-year TAS member responsible (*mwenyekiti wa TAS*) for people with albinism in the Kilolo district. For approximately seven years, Beatrice has been a politically active member of TAS and for this reason she was elected as general secretary (*katibu*) of the organization's district branch. Beatrice told me that many people with albinism do not live in suitable economic situations since they do not have proper jobs and cannot take part in the cultivation of their land or other field sites as hired hands because of the sun. Many of them rely on the support of their relatives, parents, daughters or sons. As Beatrice stated, many people with the condition do not have a secondary education, so is difficult to find other employments, for instance, as teachers.

The woman with albinism indirectly referred to victimhood when speaking about the psychological management of fear generated by the news about the murders and the marginalization of people with the condition in Tanzanian society. In her opinion, people with albinism are afraid of being killed or kidnapped by groups of men guided by local traditional healers (*waganga wa kienyeji*[6]), especially in northwest Tanzania. Economic vulnerability, social marginalization, lack of inclusion and the fear of being murdered become the main attitudes of victimhood for people with albinism. As a reaction to these social issues, Beatrice repeatedly emphasized how people with the condition "need" (*wanahitaji*) and "deserve" (*wanastahili*) that the Tanzanian governments, national organizations and NGOs provide them with proper economic and social support to lead suitable lives.

When the KCMC organized a local meeting in Ilula for "Kilisun" sunscreen distribution to people with albinism living in one part of the Kilolo district, I engaged in a conversation with Beatrice and a few others Tas members. From our group discussion, it came to light that persons with albinism should receive protection and health assistance from the Tanzanian government, just as organizations and health institutions like Utss and Kcmc are doing. Beatrice said:

> Albinos like me need sunscreen to protect their skin against the sun! […] Either you go to the field during the early hours of the day or you decide to cultivate the land during the day, you need hats and sunscreens (*mafuta*). I do not want to die while I am trying to provide food for my children! […] Agriculture is one of the few activities most of us do for earning a life in Ilula.

Deservingness (*kustahili/kuwa na haki*) and victimhood (*kuwa mw/waathirika/kuathirika na*) constitute two important arguments that Beatrice used to highlight the social conditions of people with albinism within the Tanzania public arena. Sunscreens and agricultural works constitute two intertwined instances through which these attitudes materialize. Beatrice's opinions were affirmed by the majority of people with albinism interviewed in the Iringa region and Dar es Salaam. These research participants articulated their social dispositions of victimhood by relating them to the emphasis on stigma and social marginalization and the fear of being assaulted.

Deservingness, interconnected with victimhood, is expressed as the right to equal job opportunities, improvement of economic conditions and health, and the achievement of inclusion in education and society, especially for those who suffer from violence. Instead of being empowered subjects, Beatrice and other research participants presented themselves as helpless. However, while Beatrice's main narratives and practices were partially informed by discourses of deservingness and victimhood, she also expressed diverging opinions on other occasions. For instance, she once affirmed that her life as a person with the condition could have been more difficult than it actually was. According to the *mpango wa Mungu* (plan of God), she said that she had a respectful husband with whom she had children and could live in her own house. In addition to these 'fortunes', she was able to run for a position inside Tas.

Other informants conversely contested and reformulated discourses of victimhood and deservingness more openly while elaborating alternative ideas. Emil Kindole, a 45-year-old man with albinism from Tanga, was one of the research participants who expressed such diverging discourses. At the time of fieldwork, the man worked as a *bajaji* (auto rickshaw) driver in Dar es Salaam. During his life, Emil was able to collect funds to buy an electric millstone and a small goods-wagon and establish a small restaurant in Morogoro. Emil Kindole was not part of the Tas, nor did he want to attend their meetings. "They are all the time speaking and promising things but, at the end, the Tas leaders think of themselves and their own families," Emile said to me once. According to him, life is difficult (*maisha ni magumu*) for people with albinism, but through hard work everyone can achieve his/her aims:

> I always tried to get a job and I moved around the country to get it [...]. I transported goods and products in Dar es Salaam, I worked in the field for a short period in Tanga, I drove a *bajaji* and I am still doing this. Of course, it was not easy for me as an albino to do all of these things but I was resolute to live a good life. Here in Bongoland no one present[s] you nothing, you have to deserve it!

Even though Emil is aware that he could become victim of attacks or target of mocking in Dar es Salaam and that the sun beams can damage his skin, he affirmed that through the 'will of God' and hard work (*kufanya kazi ngumu*) every person with or without albinism can have a good life.

As highlighted by Beatrice and Emile, deservingness and victimhood have distinct and reformulated semantics at an individual level in comparison to those spread by global actors. The political subjectivities of the two research participants emerge through heterogeneous and contrasting discourses and practices, although their life experiences are articulated around shared experiences of albinism. Ngos, humanitarian institutions and broadcast media generally try to portray people with albinism as victims who deserve a better future in their communities and to whom the nation state does not recognized their basic social rights. On the other hand, people with albinism articulate deservingness and victimhood in more fluid and dialectical ways through which their multiple political subjectivities become visible. Such fluid ways materialize in attitudes of either adherence to or contestation of the narratives propagated by humanitarian actors and the media.

"I do not pay attention to their gazes! I do not care!": Redefining (a)Normalcy between Albinism and Disability

My first encounter with Fidea Mbogo took place in the Tas central office inside the Ocean Road Hospital in Dar es Salaam. Fidea was born in 1987 into a middle-class family in Dodoma, the capital city of Tanzania. After achieving a bachelor degree in Accounting and Management at the University of Dodoma, she moved to Dar es Salaam to work for Sightsavers, an international Ngo for people with visual impairments. Fidea was employed by the Ngo for two years. Then, she opened a small shop in Dar es Salam to sell cosmetics, while organizing a clothing trade throughout Tanzania. Since her years in the university, Fidea has always been involved in the limited humanitarian activities of the regional and national Tas branches, such as the organization of the national day of people with albinism.

When we talk about issues related to the national and international recognition of albinism as a disability of the skin (*ulemavu wa ngozi*) and visual impairment (*ulemavu wa macho*), Fidea explained her conviction that albinism is a disability. Her main argument was that people with the condition cannot stay under the sun or perform activities as well as other persons without albinism do. Fidea questioned widespread social conceptions of normalcy and able-bodiedness that refer to people who are able to provide for their own economic and social sustainability. The woman with albinism mentioned that even though albinism was a disability of the skin and a visual impairment, the condition should not be conceived as an incapacity or inability. An example of this comes from her reference to the efforts she made during her university years to achieve results similar to her peers without albinism. During another meeting in Dar es Salaam, Fidea stated:

> You see! I am educated, I have a degree in accounting, I did internships in many important places and worked with Ngos, but I have lots of trouble in finding good job opportunities! You know why this happens … because I am an albino. There have been many times in which I sent my Cv to private companies and agencies and I got accepted for an interview. But afterwards, I did not get the job. Many people still think that albinos are not intelligent enough and are not able to accomplish work tasks or run an office.

Fidea's words sustained and reinforced a strong comparison between albinism and disability. In her opinion, albinism should be understood as a physical impairment that becomes restrictive in a disabling society. While Fidea considered that there was a strong association of albinism being a disability, she emphasized that the condition as a physical impairment can become a disability due to the restrictive social ideas, attitudes, and practices surrounding the condition as well as to issues related to the environment. On other occasions, Fidea underlined that albinism should not be conceived of as being as severe as other disabilities (e.g. deafness or blindness). If that was the case, then she would never have been able to find employment and the social position she had in society.

As shown in Fidea's case, conceptions of albinism as a disability are not univocal or static ideas that generically reverberate official widespread governmental and NGO narratives. Conversely, Fidea's ideas express the multiple ways in which the condition is conceived and thought of by the people with albinism for various political purposes and in heterogeneous social settings. While some research participants conceived of the equivalence of albinism with disability as a stigmatizing category, other interviewees used this classification for underlining their lack of social and economic empowerment in the society.

Rasmond Kinalilo is another informant with albinism who contested discourses with his words and life trajectory. He was one of the few people with albinism who openly criticized the equation of albinism with disability. At our first meeting, Rasmond was a 40-year-old man with albinism who worked as a ticket clerk and collector on a local *daladala* (minibus) from Ilula to Iringa. According to his opinion, he was a "normal person" (*mtu wa kawaida*) who suffered from none of the health problems usually associated with albinism. Therefore, he pointed out that other people always behave "normally" with him. Because of that, he was able to get his job and conduct a suitable life with his family:

> Even though my skin is white, I can walk, eat, and live as other persons do. I do not think of myself as a disabled person (*mtu mwenye ulemavu*) because I do not need any help or support from the others. […] I can sell tickets and bring people inside the *daldala*, deeds that real disabled persons cannot do. If I had the chance to get the driving license, I would be able to drive the car as well! […] Of course, people look at me sometimes in bus stations here in Iringa or Ilula, but I do not pay attention to their gazes! I do not care!

Similar to Fidea, Rasmond's words surreptitiously highlighted the disabling society in which he lived when he remarked that people stared at him in public places in Iringa. Fidea and Rasmond's thoughts on the idea of albinism as a disability demonstrate diverging conceptions of the condition. As in the discourses related to deservingness and victimhood, the understanding of albinism as a disability explains how people with the condition make sense of their social status.

The research participants are able to elaborate their own multiple political subjectivities in relation to the various ways the equation of albinism with disability is enacted or not in everyday practices (MOSER 2005). The various narratives of albinism as a disability are powerful means by which a strong sense of group belonging in people with albinism emerges. As these heterogeneous narratives materialize, albinism is conceived of as a physical impairment due to ophthalmological issues and lack of melanin in the skin. This is in addition to albinism as a disabling condition in which stigma and environmental issues play a great role by obstructing their full social realization in society (Thomas 2004; Ingstad, Whyte 2007; Goodley 2013).

Breaching Boundaries: Individual Perceptions of Belonging and Dis-Belonging

(Re)shaped versions of the selected narratives propagated by humanitarian actions and media reports catalyze various modes of belonging (Rutherford 2008) and experiential dimensions of subjectivity (Biehl, Good, Kleinman 2007; Blackman *et al.* 2008). Social practices and routinized discourses of belonging by which people with albinism make claims for resources and rights are in fact composed of three levels of identification (Yuval-Davis 2006, 2007): self, social and political. These three levels of belonging are produced by the interrelationships between the local understandings of albinism, the global flow of information and discourses on the condition, the emotional attachments to the biosocial group caused by assaults and international attention, and individual understanding of political claims.

The sense of group belonging and mobilization of political capital related to albinism emerged in a conversation I had with Fidea Mbogo. We were eating together in a small restaurant after an interview session with some informants from the national Tas branch in the Ocean road hospital in Dar es Salaam. Fidea looked around the restaurant and saw another woman with albinism eating there. She suddenly expressed a desire to greet and talk to her. To these words, she added:

> [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! When we see each other in the street or in the markets we use to chat about our lives and, also problems. […] Many of us, for example, started to attend the TAS meetings or take part in the Albinism Day.

According to Fidea, the difference between past and present experiences of living with albinism in Tanzania is the fact that people with albinism today encounter each other during public meetings held by NGOs on their behalf, share their problems, and organize humanitarian activities or self-help groups "from below." It is consequently unsurprising that Beatrice and Rasmond knew all the other people with albinism who lived nearby and within the Ilula ward. When I asked Beatrice why this was so, she replied: "I met them many times in the office of Kilolo district or when the distribution of sunscreens and check-ups of our skin conditions took place in Ilula Mwaya."

A sense of group belonging felt by people with albinism emerged through meetings and public campaigns conducted by international and national NGOs, such as UTSS, TAS and the health campaigns carried out by the KCMC. However, even though these initiatives built a strong sense of belonging and made use of the political capital of albinism for people with the condition, some of the research participants expressed doubts about the political effectiveness and moral and ethical integrity of the leaders of the national organizations for people with albinism. Such critiques directly involved TAS and underlined how biological realities about albinism, media debates, humanitarian actions and rights claims have (re)shaped a strong group belonging that exceeds meetings and public campaigns organized by national and international actors.

The sense of belonging felt by many research participants with albinism is mediated by individual formulations of politics related to economic conditions, social issues, age ranges, and subjective experiences. This is illustrated by the words of another research participant, Innocent, who talked about the complex interrelations that exist among dynamics of belonging, agency, citizenship and political subjectivities of people with albinism. Innocent was 22 years old and he was born in the local protestant hospital inside the Ilula ward. After dropping out of secondary school, he became an employee in his brother-in-law's grocery. Innocent has never been involved in the sporadic activities of the Iringa regional office of TAS. During our meetings, we spoke about diverse topics related to albinism: social marginalization and stigma, chronic socioeconomic crises, (new) ideas and concepts spread by NGOs and media campaigns. On many occasions, Innocent expressed his dissatisfaction with TAS's actions in Iringa and Ilula, which was an opinion shared by other people with albinism.

> The situation is very hard for us [people with albinism], especially here [in Ilula]. Many people with albinism live in poor conditions. Some people have small businesses (*biashara ndogondogo*) in Iringa, others get support from their families and others work on *daladala*. Others decided to work in their families' fields, even though the sun hurts their skin. […] We do not have other choices, especially if we have a family to look after. In one way or another, people have to get food. […] Albinos cannot work well under the

> sun as well as other individuals do, but many people work without being supported by their relatives. Look at my case. I am working in a shop, although the wage is very low. So, even though I am an albino, I can take part in the development (*maendeleo*) of my community.

Innocent's main argument was that Tas leaders took part in the national organization just to "steal" the funding for people with albinism made available by international organizations and the Tanzanian government. Despite Innocent's criticism of the behavior of Tas's official members his ideas about the social position of people with albinism in Tanzanian society are similar to Tas's principles. Innocent's quote demonstrates that the political subjectivities of people with albinism are mainly informed by an individual understanding and (re)formulation of the discourses brought forward by the national state and Ngos as well as strong ideas of group belonging fueled by feelings of shared social issues and life conditions.

The cases of Fidea and Innocent shows that Ngo actions and media campaigns on issues related to albinism in Tanzania (re)locate identities and differences within new political boundaries and social classifications. The productive intersections of individuals' understanding, official narratives, and political capital prompt the production of multiple political articulations of group (dis)belonging.

Conclusion: Multiple Political Subjectivities in the Making and Their Complexities

The political subjectivities of people with albinism in Tanzania are (re) shaped both within and across humanitarian discourses, practices, and ideas propagated by (inter)national human rights institutions, Ngos and broadcast media. The political subjectivities in the case of albinism result from the entanglement of global and local conceptions of albinism, the (re) production of subjectivities in "times of crisis" (Mbembe, Roitman 1995) and the consequent formation of new imagined forms of group belonging to society based on the interplay of biologies, health entitlements and citizenship rights (Biehl 2007; Nguyen 2010). The local and individual production of these political subjectivities are catalyzed when (inter)national organizations directed their attention to the attacks against people with albinism in Tanzania after the outbreak of news about these events. Assaults against people with albinism transform the bodies of people with the condition and brought attention to their human corporeality (Major, Fontein 2015) and the emergence of domains of group belonging informed by social imaginaries (Taylor 2002) and the politics of citizenship (Krause, Schramm 2011).

As the case studies and the brief analysis of humanitarian practices and discourses show, the political subjectivities of people with albinism turn around multiple individual interpretations and subjective constellations of discourses related to albinism in Tanzania, such as: deservingness, victimhood and recognition of albinism as a disability. These official narratives do not produce unified accounts, but rather served as points of discussion and debate that people with the condition criticize, (re)formulate or reproduce (Jeffrey, Candea 2006). New and already-existing political subjectivities of people with albinism emerge from the intertwining of narratives spread by humanitarian institutions/Ngos, the individual understanding of social issues connected to the condition and the multiple ways life trajectories are (re)shaped in everyday social and political interactions. Their voices, noise and silences equally constitute their political subjectivities (Schramm, Krause, Valley 2018).

Performances of deservingness and victimhood as well as the categorization of albinism as a disability can enhance a strong group belonging and catalyze the mobilization of social and political capitals. The bodies of people with albinism are thus (re)articulated as sites of political struggle and social recognition (Manderson, Venables 2015) in which questions of belonging, victimhood, deservingness and socio-moral orders are inscribed (Dilger 2008; Guglielmo 2015). Such socio-political discourses constitute the predominant symbolic axes around which political power and biological modes of belonging related to albinism strengthen the will to reformulate shared ideas of normalcy, claims of political recognition, and new forms of political belonging (Mbaye 2018) against daily hidden discrimination and silent inequalities (Friedner 2010).

Local political claims constitute the ways in which people with albinism try to discursively and practically modify widespread ideas of normalcy in society at large. Disability as well as illnesses/diseases are in fact “identified, interpreted and managed according to particular knowledge and belief systems, material circumstances [and] social institutions and relations” (Manderson 2011: 12). While relating their condition to political/humanitarian classifications, people with albinism endeavor to inscribe their condition into new imagined spaces of ableness in which normalcy is characterized by longing to appear/feel normal, social achievement/action and a conception of being able with an impairment (Manderson 2011; Harpur 2012). People with the condition also use their political subjectivities for criticizing humanitarian institutional/Ngo official narratives and practices and making sense of their life experiences. Within this process of political recognition, however, people with albinism slip and move between multiple modes of being disabled, victimized and recognized as having rights (Moser 2005). In such meaningful spaces, these persons claim their rights, express their will to be in society and navigate multiple ways of becoming visible.

Acknowledgements

I am grateful to the Daad (Deutscher Akademischer Austauschdienst) for providing generous funding for doctoral studies at the Freie Universität Berlin, Institute of social and cultural anthropology as well as the National institute of medical research, Tanzania for the ethical approval of conducting research in Tanzania. I am also thankful to the following persons for their insightful suggestions and useful comments on previous drafts of the article: Hansjörg Dilger, Aminata Cécile Mbaye, Olaf Zenker, Giovanni Pizza, Katharina Schramm, Virginia de Silva, Kristine Krause, Elisa Rondini, the participants of the Point Sud Workshop "Political Subjectivity in Times of Transformation: Classification and Belonging in South Africa and Beyond" at Stellenbosch Institute for Advanced Studies (StIAS), the members of the Arbeitskreis (Ak) Medical Anthropology at the Freie Universität Berlin, and the colleagues of the Political and legal anthropology network (Plan) at the Martin-Luther-Universität Halle-Wittenberg. Thanks go also to the anonymous reviewers for their careful reading of the manuscript. Finally, I am highly indebted to all of the women, men and children with albinism in Tanzania, who made the research possible, and my family for their support.

Notes

(1) The ethnographic research on which this article is based took the form of narrative interviews, group discussions and direct and participant observation conducted in Ilula ward, other villages of Kilolo district, in the Iringa region of the southern highlands of Tanzania, Dar es Salaam, and Moshi. The research was qualitative and exploratory in nature. The survey consisted of a multi-sited study. Participants were selected based on their status as persons with albinism, as parents of persons with albinism or simply as community members. In addition to these research participants, traditional healers, Ngo staff members and religious (Christian and Muslim) representatives were interviewed.

(2) As highlighted previously (Brocco 2015; Saffitz 2018), the biomedical category of albinism as a genetic condition is not neutral and predetermined. Rather, this category is the result of the intertwinements of violence, media publicity, and humanitarian activism. Hence, I use the term "the condition" as a synonym for albinism throughout the text.

(3) All original language terms in italics are in Kiswahili, which is the main official language spoken in Tanzania.

(4) The term "disability" has to be intended as a descriptive term that constitutes one of the social characteristics used by humanitarian actors, activists and media to situate albinism. Although there is no further space for delving deeper into the actual discussion on the term, it is important to highlight that disability as an analytical term has been articulated and (re)defined through on-going debates related to the medical model of disability, the social model of disability, and the recent emergence of critical disability studies.

(5) In order to preserve informant anonymity, all of the names used in this paper are pseudonyms.

(6) There are various Swahili words for referring to "traditional healers" and specialists in alternative medicine: *waganga wa kienyeji, waganga wa jadi, waganga wa tiba asili.* Each of these terms points to a specific and moral understanding of traditional and alternative systems of healing. *Waganga wa kienyeji,* as used by the research participants and national Tanzanian media, has a strong derogatory connotation. Even though it can be translated as "witchdoctors," I prefer using the more neutral English terms "traditional or local healers."

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Scheda sull'Autore

Giorgio Brocco è nato a Palermo nel 1985. È dottorando di ricerca presso l'Istituto di antropologia sociale e culturale della Freie Universität di Berlino e ha recentemente completato la stesura del suo elaborato finale. Attraverso una ricerca sul campo della durata di diciannove mesi, i suoi studi sono volti a indagare le pratiche sociali, politiche e morali riguardanti l'albinismo e i modi come queste sono materialmente e discorsivamente articolate da diversi attori tra spazi globali e dinamiche locali. I suoi interessi di ricerca spaziano dall'antropologia medica all'antropologia della disabilità con speciale riferimento allo studio dell'"economia morale", soggettività, incorporazione della malattia, umanitarismo, teorie critiche della debilità e disabilità e i processi comunicativi a queste connessi. Ha svolto varie conferenze e workshop in Europa e Africa e ha pubblicato articoli in riviste peer-review, giornali e blog. I suoi studi dottorali sono stati finanziati dal Deutscher Akademischer Austauschdienst (DAAD).

Riassunto

Narrazioni complesse. Incontro con le soggettività politiche delle persone con albinismo in Tanzania

Dopo la diffusione di notizie da parte dei media sugli attacchi contro le persone con albinismo in Tanzania, l'attivismo umanitario e i dibattiti mediatici hanno accelerato l'emergere e la produzione di discorsi riguardanti le persone con la condizione. Vittimismo, merito e l'equivalenza tra l'albinismo e disabilità costituiscono tre delle più ricorrenti narrazioni mediatiche e umanitarie. Attraverso i dati raccolti durante 19 mesi di ricerca sul campo, l'articolo esplora come discorsi e idee sull'albinismo sono circolate e sono state riformulate per decostruire concezioni condivise dell'idea di "normalità" e affermare la loro agentività nell'arena pubblica in Tanzania. Il materiale etnografico qui analizzato mostra in quali multipli modi l'intreccio di azioni globali con pratiche odierne in relazione all'avere l'albinismo hanno rafforzato soggettività politiche già esistenti, riformulato richieste politiche e articolato varie idee di appartenenza e disappartenenza.

Parole chiave: albinismo, soggettività politica, umanitarismo, appartenenza, Tanzania

Resumen

Narraciones enredadas. Encuentro de las subjetividades políticas de las personas con albinismo en Tanzania

Tras los informes de los medios de comunicación sobre los ataques contra personas con albinismo en Tanzania, el activismo humanitario y los debates en los medios de comunicación han acelerado la aparición y la producción de discursos sobre personas con esta afección. El victimismo, el mérito y la equivalencia del albinismo con la discapacidad constituyen tres de los relatos más recurrentes en los medios de comunicación y en el ámbito humanitario A través de los datos recogidos durante 19 meses de investigación sobre el terreno, el artículo explora cómo han circulado y se han reformulado los discursos e ideas sobre el albinismo para deconstruir las concepciones compartidas de la idea de «normalidad» y hacer valer sus programas en el ámbito público en Tanzania. El material etnográfico analizado aquí muestra de qué manera el entrelazamiento de las acciones globales con las prácticas actuales en relación con el albinismo han reforzado las subjetividades políticas ya existentes, reformulado las demandas políticas y articulado varias ideas de pertenencia y desaparición.

Palabras clave: albinismo, subjetividad política, humanitarismo, pertenencia, Tanzania

Résumé

Récits enchevêtrés. Rencontre avec les subjectivités politiques des personnes vivant avec l'albinisme en Tanzanie

Après que les médias aient rapporté des attaques contre des personnes vivant avec l'albinisme en Tanzanie, l'activisme humanitaire et les débats médiatiques ont accéléré l'émergence et la production de discours sur les victimes de ces attaques. La victimisation, le mérite et le fait d'associer l'albinisme à un handicap constituent trois des récits médiatiques et humanitaires les plus récurrents. Grâce aux données recueillies pendant 19 mois de recherche sur le terrain, l'article explore la manière à travers laquelle les discours et les idées sur l'albinisme ont circulé et ont été reformulés pour déconstruire les conceptions communes autour de l'idée de «normalité» et affirmer leurs programmes dans la sphère publique en Tanzanie. Le matériel ethnographique analysé ici montre de quelles manières multiples l'imbrication des actions mondiales avec les pratiques actuelles en matière d'albinisme ont permis de renforcer les subjectivités politiques déjà existantes, ainsi que de reformuler les revendications politiques et d'articuler diverses idées d'appartenance et de désappartenance.

Mots-clés: albinisme, subjectivité politique, humanitarisme, appartenance, Tanzanie