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Albinism, stigma, subjectivity and global-local discourses in Tanzania

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ABSTRACT

Societal ideas and explanations of albinism at the local level in Tanzania are conceived in terms of family history, social relations, economic status, moral-religious positions, global-local flows of information and humanitarian actions on behalf of people with the congenital condition. This paper aims to show how the subjectivities of people with albinism in Tanzania are shaped and re-shaped through local moral conceptions as well as globalizing (bio)medical explanations of albinism. An exemplary case study of a 28-year-old woman, plus episodes from the lives of seven other informants with the condition, are analyzed in order to understand, on the one hand, local social relationships between people with albinism and other individuals in family and community settings, and on the other hand, the interconnections between persons with albinism and global humanitarian actors and the broadcast media. When stigma and marginalizing behaviors are perceived by individuals with albinism in Tanzania as impeding their social lives, they employ different coping strategies and discourses to enhance social acceptance.

Albinism and stigma: an introduction

Oculocutaneous albinism (OCA) encompasses a heterogeneous group of congenital conditions that are the result of a genetic mutation characterized by hypopigmentation of the skin, eyes and hair (Lund 2005). Major health issues affecting people with albinism include skin cancer, nystagmus (involuntary eye movement), photophobia and poor eyesight. Albinism is present within all ethnic groups and populations worldwide, but prevalence rates are particularly high in Africa (Hong 2006; Cruz-Inigo, Ladizinski and Sethi 2011). While the prevalence of people with oculocutaneous albinism is about 1:37,000 in the US and 1:20,000 in other regions of the world, in Tanzania it has been estimated at about 1:1429 (Cruz-Inigo, Ladizinski and Sethi 2011: 79). Based on these data, it has been inferred that of the country's population of roughly 40 million, approximately 13,000 individuals have the congenital condition (Bryceson et al. 2010: 380).

Stigma and discrimination based on skin color difference, and the way this affects a person's ability to lead a full social life, are the key social issues faced by people with

albinism all around the world (Carnegie 1996; Wan 2003). The majority of people with albinism in Tanzania live in marginalized social conditions and a state of economic vulnerability because, apart from having a different physical appearance and suffering from visual impairments, they cannot actively take part in agrarian work due to their sensitivity to the sun, and this effectively excludes them from engaging in the major productive activity in most rural areas (Bryceson et al. 2010: 367).

An indication of the stigmatization of people with albinism is represented by the many denigrating labels that circulate widely in Africa. In Tanzania, the terms include *zeruzeru* (ghost), *mzungu* (white person) and *dili* (which literally means 'deal', and refers to the trade of the body parts of people with albinism on the black market).[1] This latter term is related to the phenomenon that began in the mid to late 2000s whereby 'traditional doctors' (*waganga wa kenyeji*) began to target individuals with albinism in Tanzania's northwest regions, whom they would kill in order to use their bones and blood to make amulets, which it was claimed brought their wearers luck and wealth (Bryceson et al. 2010; Schühle 2013). Following the worldwide media coverage of the murders of people with albinism, however, other labels, presumably introduced by Western educational campaigns and the media, also began to spread at the urban and rural/national level, including *mwalbino* (albino) and *watu wenye ualbino* (people with albinism) (Brocco 2015a).

This paper examines the subjectivity of a 28-year-old Tanzanian woman with albinism in relation to both stigmatization and acceptance within her family and community settings. In referring to her coping strategies, both her own explanations of albinism as well as broader social ideas around the condition will be outlined in order to highlight how albinism-related stigma, as well as strategies to gain acceptance, are formed in relation to family history, social ties, economic status, moral-religious constrictions as well as the global-local flow of information and ideas. In order to enhance the analysis of subjectivity and stigma, other episodes from the lives of seven persons with albinism will be analyzed and compared with the main case study.

International and national responses to the killings of people with albinism

The murder of people with albinism in Tanzania began to receive increased attention around 2008, when media debates and international newspapers started to highlight the outbreak of the alleged killings (Burke et al. 2014). Among the reasons cited for why the killings started to occur are the social and political marginalization of people with albinism, especially by individuals not personally familiar with them (Bratheen and Ingstad 2006), and the erosion of traditional patriarchal society over the past few decades. Under United Nations (UN) and European Union (EU) pressure, the Tanzanian government took measures against the killings. The majority of these measures were aimed at launching public awareness campaigns, creating a national task force for the purpose of suggesting ways in which to deal with the issue, identifying the murderers, suspending the certificates of traditional healers suspected in the use and trafficking of the body parts of people with albinism, nominating a person with albinism as a member of parliament, and creating boarding schools for children with the congenital condition (Salewi 2011: 37). Only a few concrete actions have followed these intentions, including the creation of boarding and special schools for children with albinism.

By far the most active and influential international organizations working on behalf of people with albinism in Tanzania are Under the Same Sun (UTSS) from Canada and Standing Voice from the United Kingdom. These international NGOs aim to improve the standard of living of people with albinism by fighting the stigma attached to the condition, promoting public awareness and education, and enhancing their overall health. The activities of these organizations have also been strongly intertwined with the interventions of national Tanzanian health institutions such as the Kilimanjaro Christian Medical Center (KCMC) in Moshi and the Tanzania Albinism Society (TAS). The awareness campaigns of these organizations all around the country have carried the message that people with albinism are as 'normal' as other individuals. The only real difference is that they are more sensitive to sunlight, and for this reason they are unable to carry out heavy work under the sun. People with albinism should therefore not be marginalized but, on the contrary, protected by their community members and supported by the government in order to create an inclusive society.

In addition to national and international NGOs, the broadcast media has also tried to promote an image of people with albinism as individuals with disabilities in need of humanitarian assistance (Fassin 2011) and protection from attack. For instance, the well-known gospel singer Rose Muhando's video entitled '*Nibebe*' (Carry me) displays children with albinism singing and dancing together with other persons with disabilities, while the hip hop group X Plastaz's lyrics for the song '*Nini Dhambi kwa Mwenye Dhiki*?' (What's the offense of the poor?) speak of 'albinos, cripples, the blind and mentally insane' as the categories of individuals that the singers claim to defend. In recent years, however, the image of people with albinism promoted by the media has changed. Instead of portraying them only as individuals with a disability in need of help, the media has started to focus on the achievements of people with albinism as a way to counter marginalization and enhance acceptance. An example of this is the internationally acclaimed documentary 'In the Shadow of the Sun' directed by Harry Freeland (2012).

Subjectivity and stigma: interrelated dimensions of albinism

The theoretical background of this article is mainly concerned with an examination of the interrelationship between individual subjectivity of people with albinism and the stigma surrounding the condition. The analysis endeavors to show how subjectivity is influenced by the experiences of everyday interactions with other people (mainly characterized by visible and invisible stigmatizing or accepting behaviors) and imagined horizons (Ingstad and Whyte 2007: 2). In so doing, the research sheds light on the self-perceptions of people with albinism regarding the condition and how this affects their daily interactions with others, as well as the societal attitudes toward them.

For anthropologists, subjectivity is seen to be not only socio-culturally created but also experiential, embodied and singular (Ortner 2005; Biehl, Good and Kleinman 2007). Subject and subjectivity are therefore not given entities but are dynamically formed and transformed within an infinite set of networks in a globalized world. Subjectivity is composed of the feelings, emotions and experiences of subjects as they are connected, embodied and projected into domestic spaces, public life, interpersonal struggles and exchanges (Biehl, Good and Kleinman 2007: 15). Hence, an examination of subjectivity has to take into account biological blueprints and bodily experience on the one hand, and the history,

political and economic position of the subjects under inquiry on the other. In this regard, through informants' subjectivities, it is possible to grasp powerful feedback mechanisms that are intertwined with structures of governance, citizenship and social personhood in relation to different health identities (Petryna 2002).

According to previous studies on albinism and original fieldwork data, the subjectivity and life experiences of people with albinism are strongly shaped by their different physical appearance and attributes. As in the case of HIV and ART treatments in Tanzania, where individuals experience stigmatization and marginalization (Mattes 2012), because of the white color of their skin and visual impairments individuals with albinism can suffer from displayed or hidden stigmatizing behaviors within their social interactions. Stigma is caused by a discrediting attribute and/or undesired divergence from social expectations (Shuttleworth and Kasnitz 2004). Stigma can be defined as a social product that is not only attached to individual bodies but is located within impaired individual networks of social relations (Das and Addlakha 2001), which draws on norms and values in a way that results in the social exclusion of the stigmatized person(s) (Goffman 1963; Gregg 2011). Apart from having social and temporal dimensions, because of particular social values and norms, stigma also has repercussions for the subjective experience of affected individuals (Yang et al. 2007). Stigma and subjectivity are thus closely intertwined. Individual subjectivity can be modified by marginalization in social life, just as stigma can be nurtured or successfully coped with through statements, opinions and the formation of certain identities (Whyte 2009) originating in the social dimensions of a person's subjectivity, namely the family, neighborhood, community members, the national and international media, organizations engaged in 'identity politics' (Anspach, 1979) and informal support groups (Ablon 2002; Shuttleworth and Kasnitz 2004).

Research methodology and background of the study

This paper draws on 11 months (2012−2014) of ethnographic fieldwork on albinism in Ilula ward (*kata ya Ilula*), other villages of Kilolo district, and the municipality of Iringa within Iringa region, south-central Tanzania. The research used both formal (structured and semi-structured) interviews as well as focus group discussions with people with albinism, their relatives, NGO staff members and religious leaders. In addition, the researcher took part in home group meetings and everyday life situations of people with albinism in rural areas. Although many persons, especially elderly individuals, spoke Kihehe in their everyday lives, interviews and group discussions were conducted in Kiswahili (the main official language in Tanzania) and/or English.

Kilolo, one of the three districts of the Iringa region, is mainly populated by the Hehe people. It is also an area where no killings of people with albinism have been reported. This apparent difference from north-western regions such as Shinyanga or Mwanza − where most of the killings of people with albinism have been reported over the past years − can be ascribed to two main reasons. First, in the region of Iringa there are no major diamond or gold mining centers. In other areas, mining for such valuable minerals prompted the desire for lucky charms and 'magical protection', which could take the form of amulets made of the bones or blood of people with albinism (Bryceson et al. 2010). Second, according to some informants in Iringa as well as in Dar es Salaam, belief in the 'magical power' of traditional healers is more widespread in the northern regions.

The intertwinement of subjectivity and stigma in the life worlds of people with albinism is analyzed in this paper through the case study of 28-year-old Julieth from Ilula and the accounts of other seven informants with the congenital condition. Julieth's story resembles the life experiences of other people with albinism in Kilolo district and the Iringa region in terms of how she has (re)defined her subjectivity in relation to both her social relations and global flows of information on the condition, as well as in terms of how it reveals her never-ending struggle to successfully cope with disturbing episodes of stigmatization. Her case study also differs from the life stories of other people with albinism, in terms of the inclusive and stigmatizing behaviors faced, although references to experiences in her childhood still convey some of the problems that many children with albinism must deal with. The peculiarity of Julieth's story stems from the ways in which it illuminates the process of the making and unmaking of an individual's subjectivity (Biehl 2005; 2007) in relation to heterogeneous social contexts (i.e. her complex network of family relations, her work experiences, the stigma attached to her condition), as well as to global-local interactions, including (bio)medical explanations, religious discourses, international and national information, and collectively held ideas around albinism.

The analysis of the intertwinement of stigma and subjectivity is further enhanced through brief references to the life experiences of other seven informants, selected among 30 interviewees with albinism, which shed further light on the themes of gender, social class and family life. Of all of the respondents, seven (three women, three men, and one male teenager) lived in small villages in Kilolo district, while one lived with his family in Iringa town. While two of the women and the male teenager had no employment, one man and one woman cultivated their own land, one man worked as a clerk in a shop and another man worked as a school teacher in Iringa.

The formation of subjectivity through family acceptance

Julieth,[2] a 28-year-old woman with albinism, was born and had always lived in Ilula, a small city (*mji mdogo*) along the paved road from Dar es Salaam to the municipality of Iringa. She shared her rented mud-brick house near the Ilula Catholic Mission with her five children. While her four sons were too young to go to school, her 13-year-old daughter from a previous relationship attended the Ilula Mwaya Primary School and occasionally helped her mother to look after the fruit and vegetable stand that Julieth had opened up in 2012, but which she was forced to close in 2013.

Julieth lived close to her mother, with whom she had always had a good (*nzuri*) relationship, a fact that she emphasized many times. Her mother (*mama*) and father (*baba*), the latter of whom had died in 2007, were really 'happy to have a female child with albinism' and had always taken good care of her since birth. Julieth considered her parents' attitude towards her as an exception, since:

> In the past people with albinism like me were killed at the time of their birth. Their family members, when they saw them for the very first time, usually took the decision to strangle (*kunyonga*) them, because the majority of people thought that the presence of such an individual within the family could constitute a curse (*laana*).

Julius, a 17-year-old boy from Luhindo, a small village in the southern part of Kilolo district, unfortunately did not share a similar destiny. He recounted how his father did

not accept him when he was born and had blamed his mother for the color of his skin. After his mother had died, 'my father repudiated me and threw me out of his house. When we lived together, more than one time, he expressed the wish to kill me or to leave me in the forest. For this reason, since then I have been living in my mother's parents' house.'

Notwithstanding the fact that albinism is often considered a curse and damaging to the social reputation of the entire family, Julieth's parents did not endeavor to kill her after her birth, nor did they marginalize her, as she repeatedly pointed out. Indeed, on two occasions Julieth's father overtly demonstrated his love of his daughter, to the extent of defending her against the views of some relatives on his kinship side who had tried to persuade him to disown her:

> One of my uncles on my father's side, more than one time, said to my mother when I was only a child to throw me away because of my odd appearance, having white skin and a face looking like that of a fish […]. Another uncle also suggested leaving me to my destiny without taking care of me […]. God punished both of them, as their wives gave birth to children with albinism some time later.

Aside from the comment that God had punished her uncles' negative attitudes towards her by sending them children with albinism of their own − a suggestion of the moral-religious implications surrounding the etiology of albinism that I address in more detail below − an important point that emerges from Julieth's quote above relates to the reactions of her extended family. These reactions, which were not so different from what other people with albinism reported during the fieldwork research, reveal how attitudes towards albinism are affected both by family histories and characteristics, as well as by broader kinship structures.

Julieth and all of the interviewees belonged to the Hehe ethnic group, which mainly lives in small villages within Kilolo district and is characterized by strong male dominance and a patrilineal inheritance system (Swartz 1969: 84). An indirect link to patriarchy and patrilineality can be traced in the fact that although mothers were said to always be fond of their children with albinism, the ultimate decision of whether or not to reject them lays in many cases in the hands of the father. Novetha, the 'black-skinned' mother of two children with albinism, was in fact abandoned by her husband, a local primary school teacher, when she gave birth to her second son with the condition. Novetha said, 'I have been living in my parents' house since my husband and his family convinced themselves that I am a sick person (*mtu mgonjwa*) unable to give birth to normal children (*watoto wa kawaida*).' It can therefore happen that children with albinism are welcomed by their mother's family yet excluded by their father's relatives. This interestingly goes against the Hehe patrilineal kinship system, in which the brideprice is transferred to the mother's family 'in return' for the children born in the marriage, who will subsequently belong to father's clan.

The findings also show that in cases where there were no other persons with albinism in past generations or within the kin ties, it was more likely for children with albinism to be marginalized and for their mothers to face rejection. Rejection of the mother resulted from numerous ideas that linked the mother to the appearance of the condition, including ideas that albinism is a divine punishment for her past misdeeds or that it is the result of a lack of iron (*madini*) in the blood she passes to her unborn baby. The mother is usually

blamed by her husband's relatives first, and consequently by a part of the community, for being the primary cause of the 'abnormality' of the child. The most frequent epithet used for the mother is 'sick person' (*mgonjwa*), as it was in Novetha's case.

Alternately, it could happen that individuals with albinism were easily accepted within their family if there were already persons with the condition among their kin relatives and/or if the grandfather affirmed in front of all the relatives that the child belonged to the family and resembled other family members. The latter point hints to the continuing significant role that grandfathers (and grandmothers) play within family networks (F.E. Brown 1935). Mwakatwila, a 23-year-old man with albinism who lived in Ilula Mwaya, for instance, recounted how:

> My mother told me that when I was born many members of my family started wondering why I had white skin. They posed many questions to my father and my mother but, in the end, all of them accepted me when they discovered that the sister of my grandfather on our female family side (*bibi*) had albinism too, and my grandfather stated that because of my look (*kwa mtazamo wangu*) I had to belong to our kin group (*ukoo*).

Julieth's case, however, diverges from the idea that in families where other kin members with albinism are present, or where grandfathers intervene on their behalf, babies with albinism are more likely to be accepted. Notwithstanding the fact that her parents had no relatives or kin members with albinism, they still decided not to reject their daughter. This decision, according to Julieth, was taken in contrast to the moral and social values shared by their relatives, who endeavored to convince them about the improperness of such a decision. Julieth's case therefore also provides an account of the apparent confinement of non-stigmatizing attitudes to her close family circle, i.e. her parents/nuclear family composed of her *mama* and *baba*. Although it has been argued that people with albinism often feel accepted and included in familiar settings and especially within their families (Braathen and Ingstad 2006: 610), as Julieth's case demonstrates, it is perhaps necessary to specify and distinguish between the different levels of the 'family' (*familia*) and kin group (*ukoo*).

'They cannot poke fun at me': fighting stigma and socio-economic obstacles on a daily basis

Stigma towards people with albinism can be caused by many factors. Even though there are individuals, especially strangers or those unfamiliar with people with the condition, who perceive albinism as an abnormal condition, others may start to stigmatize an individual with albinism due to external reasons, be they of a social or economic nature. An exemplary case of this is represented by the last man with whom Julieth was engaged and with whom she had lived for many years. Julieth described the beginning of her relationship with this man, whom she referred to as husband (*mume*), as having been quite good. After a couple of years, however, it grew worse little by little. As she explained:

> My husband began cheating on me and beating me up when totally drunk. Since rumors of albino killings have been broadcast throughout the nation, he even began intimidating me by saying that he should sell my body to traditional healers (*waganga*) in order to earn a huge amount of money. I could not cope with the situation any longer and, for this reason, I decided to report my husband's intentions and behaviors at the nearest police station. He was found guilty and imprisoned.

In spite of the fact that she knew that if she reported him to the police and had him incarcerated he would most likely leave her, disown their children and no longer help her financially, Julieth nevertheless went ahead and did so. Indeed, after he got out of prison he did break off the engagement and left her and the children alone without support. Even though there have been no reports of killings of people with albinism in the Iringa region so far, threatening statements, such as those pronounced by Julieth's ex-husband, testify to the imaginative power that the media reports concerning the sale of the body parts of people with albinism exert on local perceptions of the condition. A similar issue was faced by 40-year-old Neema from Utengule. She said that she had been threatened repeatedly by her husband. She recounted that 'when my husband got to know the price of my body parts, he told me that he would sell me to a traditional healer (*mganga wa kienyeji*) in order to earn money.' Like Julieth, Neema reported her husband to the police. According to her, her husband had threatened her 'because we were really poor, and since his death, we have not had anything else to feed us and our children.'

Baraka, on the other hand, a 35-year-old middle class teacher from Iringa town and general secretary of the TAS regional office, had a different experience. As he explained, 'I never faced any problem in dating my future wife, neither from her nor from her family. They have always been happy to have me as the husband of their daughter.' Baraka came from a wealthy family in Njombe and had had the opportunity to earn a Bachelor's degree in Education. This title had allowed him to obtain a position as a teacher in Iringa and therefore to make a decent living. His relatively positive experience of acceptance by his wife and her family, in contrast to the experiences of Julieth and Neema, thus show the importance of economic factors, media reports, gender relations and widespread conceptions of albinism in terms of how they affect acceptance or rejection behaviors as well as how they generate or reduce stigma towards people with albinism.

Another social setting in which individuals with albinism can suffer from stigma is in school. For Julieth, when she went to school she was part of a large class crowded into a single classroom, and since she had no glasses she had tremendous trouble seeing the blackboard from a distance. Due to these challenging conditions, her subsequent poor grades and the economic incapacity of her parents to pay for private secondary school, Julieth dropped out after finishing the primary classes. During her education, she experienced a predisposition on the part of her teachers that was unsuitable to her needs and challenges. She said in fact that, 'neither did someone explain to me what albinism is, nor did the teacher ever say something about my condition in the classroom.' Psychological and physical victimization, such as bullying and name calling from other students, worsened her experience in school. She recounted that, 'when I was at school, some children mocked me because of my skin and because I could not attend the lessons very well. It was not my fault that we were too many in my classes.' Such behavior on the part of her peers presumably occurred because of negative social ideas and discourses about people with albinism, combined with the lack of available (bio)medical information about the congenital condition at the local level, as recounted by Julieth.

Most families of people with albinism in Africa, including Tanzania, do not possess the economic means and/or occupy a suitable social position to send their children with albinism to (an appropriate) school (Bryceson et al. 2010; Baker et al. 2010; Braathen and Loeb 2011). Without a proper education, individuals with the congenital condition, both

men and women, consequently cannot aspire to employment other than cultivating their own field, working on the land of others as hired hands or performing various manual jobs under the sun, even though these activities are particularly dangerous for them due to their skin's sensitivity to sun exposure. Forty-four-year-old Deo from Magome, a small village in the southern part of Kilolo district, recounted such difficulties. Even though he had been suffering from a large and visible skin cancer that covered part of the left side of his face and ear, he had continued to work on his family's field until his death in 2012. Before he died, Deo recounted that he worked on the land because: 'agriculture is how I can take care of my wife and my children. They have to eat in one way or another!'

Julieth in turn had similar experiences. Without a suitable education, she endeavored to make a living by engaging in various forms of manual work incompatible with having albinism. For instance, after leaving school and spending some time at home helping her parents, she decided to trade in charcoal. In one meeting she said:

> Before starting my business, I tried to sell charcoal that I bought every day and carried on my back to Ilula. I had to leave that job because the transportation of charcoal under the sun had hurt me so much that I could not afford it anymore. Because of that, I took the decision to open a small fruit and vegetable shop with my savings.

Julieth nevertheless explained how difficult it was to get the business going: 'I am trying to start my own business. At the moment it is really difficult. Sometimes it goes well, other times not. But this is the only possibility to feed my four children and pay the rent of my house.' Indeed, in November 2013 she was forced to close the stand because nobody wanted to buy her products. People in Ilula were apparently afraid to touch (*kugusa*) products or drinks such as tea (*chai*) that had been handled by a person with albinism. As a result, and despite the physical problems that such an activity posed for her, she therefore had to resume transporting charcoal and had also started selling large stocks of plastic bottles and/or onions out of one of the rooms of her hut.

Ideas and discourses on the 'social awkwardness' surrounding albinism, such as those that caused the closure of Julieth's stand, have also been documented in other African countries (Baker and Djatou 2007). Further proof of this from the current research also comes from Rebeka, the general secretary (*katiba*) of the TAS division for Kilolo district. She was a 47-year-old widow who earned her living by selling the fruits and vegetables that she grew on the field that she acquired from her late husband. In 2013, Rebeka also tried to sell small prepared food products such as *bagia* (fried mixed beans), *mandazi* (fried bread), *chapati* (flatbread made of wheat flower) and *chai*, but as she said, 'I gave up because people did not buy these things from me, maybe they were afraid of touching and eating them… I do not know!'

In the case of Julieth, she never tried to emphasize the severity of her social and economic situation, nor did she blame it on her albinism. On the contrary, she underlined over and over again how she endeavored to convince other community members that she was 'normal' (*wa kawaida*). The only difference between her and others, she used to repeat, was the white color of her skin. Even though there were many individuals in Ilula, both older and younger, who did tease her due to her physical appearance, there were nevertheless many others, such as her neighbors, with whom she had good relationships.

'Only God knows the reason why my skin is white': religious explanations for albinism

> Everything is a plan of God. It is always God who is the one who gives and concedes. Everybody is a human being and can stand alone and be self-sufficient and God thinks of each of us […]. God sees everything. When other persons say bad words against me, I am sure that God won't bless them but punish them.

Such sentiments were expressed by Julieth on several different occasions. They profoundly testify to her close relationship with God, the only one who, according to her, had decided to create her with albinism. Like Julieth, most of the informants and interviewees also thought that albinism is the plan of God (*mpango wa Mungu*) or a condition that is the work of God (*kazi ya Mungu*).

The recourse to God in order to explain albinism was also linked to the affiliation of many people with albinism to one of the multiple Pentecostal/Evangelical churches in Tanzania and the Iringa region. Julieth was no exception. For almost ten years, she had been a member of the Ilula church of the Assembly of God, and seven years prior had been 'reborn' (*kuokoa*) and 'saved', as the local pastor (*mchungaji*) had asserted. Like many other Tanzanians, Julieth had decided to become a member of one of the many Pentecostal churches present in Ilula not only because it preached to offer well-being against devil forces, but also because of the relief activities carried out by the church for its followers, providing them with new opportunities in situations of powerlessness and need (Dilger 2007). Such politics of identity and belonging (Mayer 2012) that Julieth shared with other adherents of the Assembly of God manifested itself when she had to go to the KCMC for her first surgical operation to remove a small skin cancer on her neck. Other followers of the church had collected the money for her travel costs and accommodation expenses in Moshi. At other times as well, Julieth said that, 'the pastor and the others are always ready to give me a little help (*msaada mdogo*) when I need it.'

Julieth's affiliation to the Assembly of God as well as her belonging to the Hehe ethnic group also help to explain her views about the moral-religious etiology of albinism. Among the Hehe people of the Iringa region, God (*Mungu*) is believed to be the primary source from which all creatures originated (Feierman 1981: 355). As God is believed to have a purpose and plan that is totally unknown to any human being, congenital conditions, which are caused by his will, must therefore also fall under the normal course of things. When asked what Julieth usually said to individuals who made fun of her, for instance, she replied:

> When I hear strangers (*wageni*) pointing at me as a *mzungu* (white person) or *dili* (deal), I basically try to explain to them that I am a normal woman (*mwanamke wa kawaida*). God decided the whiteness of my skin! I am a creature of God (*mimi ni kiumbe cha Mungu*)! They cannot poke fun at me. If they keep misunderstanding my words then I start ignoring them. It is the only way.

Furthermore, since albinism is the will of God, Julieth also talked about how those who addressed her with denigrating labels or mistreated her due to her condition would be punished by God.

However, as with the categories of maladies such as illnesses of man (that are brought about by sorcery) or illnesses of spirits (*mashetani* or *majini*), illnesses and diseases caused by God are also believed to have moral implications (Feierman 1981; Dilger and Luig

2010). Collective and individual thoughts about God as the ruler of the world in fact testify to the moral character of disability and illness, which is conceived within the local moral world as a punishment for improper actions (Kleinman 1997). The idea of disability as a punishment emerged on several occasions during the research, although with different emphases. According to the pastor of the Assembly of God in Ilula, for instance, albinism can be seen as a manifestation of misdeeds within a family. Julieth, in turn, echoed this sentiment; as illustrated in the quote above, when she was speaking about how her mother and father had come under pressure to abandon her due to her condition, she spoke of how God had punished her paternal uncles by sending them children with albinism of their own. The religious-moral implications of albinism are therefore twofold. According to many, albinism is the will of God, even if his reasons for it are unknown. For Julieth, this view may have helped her 'to personalize the meaning of [albinism] and manage stigma' (Stanley 1999: 114). Yet the comments of Julieth and others also confirmed the moral etiology of the condition, with it being defined as a curse and/or divine punishment for unethical attitudes.

'I am a disabled woman': the global-local flow of ideas and discourses on albinism

In addition to the influence that Julieth's religious and ethnic affiliations had on her attitude towards albinism, awareness campaigns and public debates on radio and TV programs also provided her and other persons with albinism with new strategies and ideas with which to act upon stigma and search for her rights. Even though Julieth claimed that she had never obtained biomedical information on albinism, since around 2008 she had been in contact with doctors at the Kilimanjaro Christian Medical Center (KCMC) for her three surgical operations, as well as with Sista Bukombe from the order of St. Thérèse of the Child of Jesus, who on behalf of KCMC distributed sunscreen twice a year within the district and carried out dermatological check-ups among people with albinism. Julieth was, furthermore, occasionally exposed to the activities of the district and regional staff members of the Tanzania Albinism Society (TAS), which were carried out on behalf of people with albinism within Kilolo district. Sporadic meetings at the Kilolo district office were organized for the distribution of sunscreen, for instance, and in order to offer instruction to people with albinism regarding their safety when the killings in Tanzania had become a major issue in the country. Julieth did not, however, actively take part in TAS activities. Primarily, she thought that the TAS leaders, especially at the district level, were corrupt persons who just 'wanted to eat money' (*wanataka kula pesa tu*). Furthermore, she also expressed once that 'I cannot afford to deal with other peoples' problems because life is hard (*maisha ni magumu*) and I have to work every day.'

Julieth's detachment from the TAS did not prevent her from getting in touch with other individuals with albinism with whom she developed a group identity based on having the condition, as well as on the shared belief that they were living with a disability and their commonly held values and ideas about their normalcy. Their shared physical appearance and economic problems also catalyzed the creation of such linkages among people with albinism in Ilula. Julieth showed a poster that she had obtained after a meeting at the Kilolo governmental district office, which had been produced by the NGO, Under the Same Sun (UTSS), that illustrated the articulation of these new identities. On

the poster was a dual language statement from the NGO's founder, in which he expressed his wish to see social equality and an end to discrimination against people with albinism all around the world in the immediate future. When asked whether she thought of albinism as a disability, and of herself as disabled, Julieth instantly replied, 'Yes, of course I am. I cannot work in the fields under the sun as many other persons do and I cannot see at a distance. So I am a disabled woman.' The fact that she was a disabled woman was a claim she made on other occasions too. The discourse of values and rights spread and promoted by international organizations (Ingstad and Whyte 2007) such as UTSS have thus developed a particular identity among people with albinism at the local level in Tanzania, based on the claim that albinism is a disability (Brocco 2015b). At the same time, this new identity has strengthened connections among people with albinism based on common aims, physical features (e.g. their white skin) and life challenges. Nevertheless, even though Julieth seemed to share the ideas spread by the media and NGOs that people affected with albinism are 'normal' and as deserving of rights as any other person, more than once she affirmed that she would not want have a child with albinism, 'because I am aware how life in Tanzania is hard for us.' This comment confirmed that stigma and difference persist despite the widespread shift in rhetoric.

Conclusion: albinism, subjectivity and stigma

The analysis based on Julieth's case study illustrates that individual and moral concerns – created by family ties, economic situations, friendship relations, intersubjective experiences and religious-moral thoughts – influence the social and psychological management of living with albinism in Tanzania. Shifting thoughts and feelings about the congenital condition also play an important role in countering stigmatizing behaviors in a context where individual subjectivity becomes increasingly enmeshed in the global flow of information and the broader political economy, as well as in local discourses and collective modes of thinking (Biehl, Good and Kleinman 2007). In this regard, the research highlights the close interrelationship between processes of stigmatization and social inequality, since Julieth and most of the people with albinism in the study were living in a state of severe poverty and vulnerability; a social position that is also shared with many other individuals living with albinism in other African countries (Braathen and Loeb 2011).

Social discrimination and stigma are strongly linked to social hierarchies and the unequal distribution of economic and political power (Songwathan and Manderson 2001; Link and Phelan 2001). On the one hand, albinism, as with other conditions of illness and suffering (Weiss et al. 2001), enhances vulnerability and affects the social status of a person. On the other hand, religious discourses – i.e. that albinism is God's will, as evoked by the Pentecostal church – along with the humanitarian rhetoric of transformation – i.e. the self-conception of albinism as a 'normal condition' and/or a disability, as promoted by national and international organizations – are a means through which people with albinism in Tanzania can develop a self-identify imbued with the 'positive' values of their condition, promote self-empowerment and counterbalance stigmatizing behaviors. Family attitudes and the belonging to social support groups (such as religious congregations and/or community-based organizations) are also factors that contribute to the formation and transformation of the subjectivities of people with albinism with regard to the creation of a group identity.

In order to shed further light on the experiences of living with albinism in Tanzania and other African countries, more systematic studies are needed in future. For instance, a focus on corporeality (Venables and Manderson 2015) and practices of albinism could be a valuable line of research. This path of inquiry might enhance our understanding of forms of affiliation, self-practice and sociality based on 'having albinism', as well as of the struggle of persons with the condition to be recognized as 'normal individuals' and to achieve social acceptance. In relation to this, a further examination of the interconnections between local and global moralities, existential uncertainties and vulnerabilities might enhance our insight into the everyday struggles for inclusion carried out by people with albinism in the wake of humanitarian actions.

Notes

1. All original language terms in italics are in Kiswahili, which is the main official language spoken in Tanzania.
2. All names used in this article are pseudonyms.

Ethical approval

The National Institute of Medical Research (NIMR) provided ethical approval for the research. Written and oral consent for observation and interviews was also obtained from each study participant.

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