UPPSALA
UNIVERSITET

Department of Theology
Fall Term 2022

Master's Thesis in Religion in Peace and Conflict
30 ECTS

“I Will Tell Your Story”

Making and Using an Ethnographic Portrait of Tanzanians with Albinism

Author: Linnéa Román
Supervisor: Brian Palmer

Abstract

This thesis is both an ethnographic story about people with albinism in Tanzania and a reflection on how that story may be used to generate understanding and support in the wider world. In much of sub-Saharan Africa people with albinism face discrimination and even violence at all levels of society. During seven months in 2021/2022 I lived in northern Tanzania and regularly spent time with a community of children with albinism and the woman who shelters them. I got to know these individuals through conversations, interviews, grocery shopping, cooking, and eating together and celebrating Christmas and other holidays. All the while, I also sought to be in solidarity with my hosts, by telling their story in various forms and raising funds for them in Sweden. A central research question of the thesis is how one tells a story about vulnerable individuals without diminishing their dignity or violating ethical standards of academia, journalism, and humanitarianism. I consider four types of public response to my various acts of ethnographic storytelling, and I reflect upon persistent dilemmas.

Keywords:

Albinism • Ethnography • Humanitarian Appeals • Instrumentalising Rumours • Tanzania

www.linnearoman.com
contact@linnearoman.com

Acknowledgement

Where do I begin? How can I write an acknowledgement that embraces the more than one hundred persons who are the reason for this ethnographic work? I would like to name everyone, which of course, is not possible. But perhaps it is enough that you – who lent your sun lotion, donated money, or bought an Albinism Awareness product – know that it is because of you that we were able to help support Sr. Martha and the children with albinism in Tanzania. I can tell this story because you cared, and I am forever grateful for that.

However, telling the story of people with albinism would not have been possible without Sr. Martha and Brian Palmer.

Sr. Martha, who welcomed me, a stranger from Sweden, into her life. She let me ask countless questions, invited me to her home and answered all my WhatsApp calls, even when I had travelled back home. I am thankful for our friendship.

Brian Palmer has with great dedication and patience, supervised this project from the initial idea that emerged in September 2021 to the finished product in 2022. It has been a true privilege.

Foreword

The children are watching the television in the next room from where I am staring at a pile of clothes in front of me. I am exhausted and emotionally drained after a couple of intense days collecting research data. The curtain that works as the room's door flutters and a girl nicknamed Small S moves stealthily towards me. I look up and see how her little hands crack the biscuit she received in Sunday School. She hands me one of the two pieces and gives me a compassionate smile before she walks out the room and joins her friends.

Like Small S, this thesis is a story about 85 ordinary people who decided to share their biscuit with someone else. Sister (Sr.) Martha decided to share a fraction of her life with me. I decided to re-tell and share her story on my social media accounts. And 83 individuals saw someone in need and donated money or bought products to support Sr. Martha's work. This story knots the strands of 255 lives together because the generosity showed, reached to 170 people with albinism in Tanzania.

But the thesis is not just an analysis of a project that began in May 2021. It is also a reflection about a researcher's participation and engagement with her subjects as much as it is an academic reflection on fundraising appeals, humanitarian photography, charity giving and ethical dilemmas. How does one tell a story about people with albinism that will engage the western public without diminishing their dignity or violating ethical standards?

As many might recognise, the title for the thesis – "I Will Tell Your Story" – comes from Laleh Pourkarim's song "Some Die Young". Sr. Martha has told me stories of people with albinism that are essential for the study's data collection. Equally, I have re-told the stories of Sr. Martha to create engagement and raise albinism awareness in Sweden.

You, as a reader, are part of this story too: your questions, disagreements, emotions, realisations, and concerns will carry the thesis to further places where it can have an impact on research, marketing strategies, policies, activism and for the life of people in different humanitarian situations.

Acronyms

ATR	African Traditional Religions
CWA	Children with Albinism
NGO	Non-governmental Organisation
OA	Ocular Albinism
OCA	Oculocutaneous Albinism
PAC	Peacemakers for Albinism and Community
PWA	People with Albinism
SSA	Sub-Saharan Africa

Table of Contents

Chapter 1. Introduction

A bumpy road leads up to her house. Lomo, the taxi driver, parries between the holes on the ground while he and Sr. Martha are talking. I am seated in the backseat and snatching up a few words of Swahili from their conversation. The big tree next to her small house appears as a firm and kind giant guard. Twenty children – of whom some stay with her, and some are her neighbours – play football in front of the house but stop once the car appears on their playing field. They do not back off or run away to play somewhere else but approach the vehicle. Sr. Martha gathers her belongings, thanks us for the ride and opens the door; 20 faces greet her with smiles, and each of them says: *"Shikamoo*[1] *Sistha"*. Once outside, the children assemble around her body: tiny fingers reach out for her hands and dress: some of them carry her heavy luggage while a boy takes Sr. Martha's handbag and places it on his shoulder before the two of them follow the rest of the children towards her home.

Sr. Martha welcomes any vulnerable child in need for advice or a guardian. I met many of the children during my time in Tanzania. This is how I described the girl child I call Small S:

> Small S has beautiful, twinkling eyes that "dance". Her hands are tiny and give a thumb up when she spots someone with a camera. Those hands break a biscuit and give me half of it. She will stay at her grandmother's place for a couple of days during the Christmas break to see her family and siblings; overjoyed; excited. The first night passes and Sr. Martha receives a call from the grandmother; they – Small S and grandma – have not slept. The grandmother re-tells how Small S hid under the bed when three unknown men arrived on a motorbike with a box, asking the neighbours: "Where is the white girl?"
>
> Sr. Martha realises it is not safe for Small S to stay with her family. What if something had happened? If Small S had been kidnapped? Or worse, killed? (Translation from Facebook post published 17 January 2022: see Román, 2022)

---

[1] Swahili greeting of respect to an older person.

Sr. Martha is one person among estimated 4,000-173,000[2] Tanzanians with albinism. She is the founder of the organisation Peacemakers for Albinism and Community (PAC) and has devoted her life to supporting and protecting adults and children with albinism living in northern Tanzania. PAC works to raise community awareness, support education and training for people with albinism, promote skin cancer protection and give students with albinism access to safe schools. In total, 96 children with albinism are included in the programme to access education. Another 30 adults with albinism who are entrepreneurs (e.g., tailor, farmer, businessperson) receive advice and training from time to time.

I met Sr. Martha for the first time on May 11 (2021) during an interview for a course assignment within the programme I am studying. The course aimed to collect data for a small-scale research project and communicate findings in a popular scientific format (Román, 2021c). Later, I described the meeting with Sr. Martha on Facebook and Instagram. I hoped the post would spark empathy amongst my followers to support Sr. Martha and PAC with sun protecting means. Within one week, 13,691 SEK (1,362 USD[3]) had been raised to buy sun lotions and sun hats for children with albinism (CWA). I was overwhelmed with the response and empathy the public had shown towards a stranger.

1.1 Aim of Thesis and Research Question

This ethnographic study is in part about a woman's efforts to protect and shelter children with albinism in Tanzania. It is also about the donor giving it led to in Sweden because of digital storytelling. It tells the story of events and contemporary struggles for individuals with albinism and presents various ways Swedes came to engage and learn about Sr. Martha's work.

---

[2] A lack of accurate statistics makes authors estimate the frequency of albinism differently. Only one source, the organisation Under the Same Sun (UTSS), demonstrates their calculations. For instance, articles in the late 2010s from BBC (2009) and Malone (2009) suggested that 17,000 PWA lived in Tanzania. Meanwhile Netema (2008), Obulutsa (2009) and Ravi (2009) suggested it to be 170,000 or more. Based on the national population from 2012, UTSS (2012a) estimated that at least 30,000 individuals with albinism live in Tanzania. Their calculations ground on a prevalence of 1 in 1,400 as estimated by Luande, Henschkle and Mohammed (1985, cited in UTSS, 2012a) at the Tanzania Tumour Centre in Dar-es-Salaam. Since it is unclear how the estimation of 170,000 has been made, I believe the most accurate prevalence of albinism in Tanzania span between 1 in 1,400 to 20,000 people. Based on the national population for 2022 (World Population Review, 2022) it suggests that 3,300-46,800 PWA live in Tanzania. But even 46,800 might be an underestimation of the prevalence as it does not account for infanticides.

[3] Converted from SEK to USD, 12-06-2022. A total of 46 Swedish citizens (37 women and 9 men) donated.

The objectives of the thesis are threefold. First, the thesis sheds light on human rights violations against people with albinism (PWA) by describing my observations while conducting ethnographic fieldwork in Tanzania. Second, the thesis discusses contributing factors that justify mutilation and killings of PWA and argues for the need to invent and use the umbrella term – "instrumentalising rumours" – to acknowledge the complex reality of interconnected factors that influence people from varying groups to believe body parts from PWA possess power. Third, the thesis assesses ethical dilemmas arising with different strategies to convey messages that will engage the public about vulnerable groups and humanitarian situations. A question regarding public engagement and humanitarian photography that I find particularly interesting is: should one sometimes violate ethical standards if it results in donor giving?

The study adopts an ethnographic research design to answer the research question: how does one tell a story about people with albinism that will engage the western public without diminishing their dignity or violating ethical standards?

Concerning the research question, I like to clarify a couple of concepts. Firstly, "engage" refers to the action of "causing someone to become interested or involved in an activity" (Cambridge Dictionary, 2022a), in this case, to support people with albinism. I further categorise and define four types of public engagement that show how people came to get involved with the work of Sr. Martha. Secondly, when using "dignity", I refer to the concept of human dignity as "the belief that all people hold a special value that is tied solely to their humanity". Hence "by being human, all people deserve respect" (Human Rights Careers, 2022). Thirdly, The thesis draws upon ethical standards including rules and guidelines for conducting research at Uppsala University (2022), the General Data Protection Regulation (GDPR), Swedish ethic codes for taking and publishing photos of children as well as my own understanding of ethical responsibility. To uphold good research practice, I apply Swedish ethical codes to my photographic work even though photos have been taken in Tanzania[4].

For this research I have conversed, interviewed, observed, and participated in the work of Sr. Martha during two research periods [5] in Tanzania. However, our contact and my ambition to raise albinism awareness is not limited to a specific time and space. It began in

---

[4] A code of ethics for media professionals has been produced by the Media Council of Tanzania (MCT, 2016), but focuses on broadcasters and press photographers, thus trained journalists. However, I use this as a principle for general guidelines on coverages involving children (4.12 in MTC, 2016).

[5] First (1) period in May 2021, second (2) period from October 2021 to March 2022.

May 2021 and has not stopped as of November 2022 and is reflected by the study's intensive and copious data collection.

Like many ethnographies, there is a greater focus on providing detailed descriptions of people, their interactions, and their milieu rather than a focus on theorising. Nonetheless, like most ethnographers, I am interested in reflecting theoretically on a few questions of particular interest to me, such as the main research question, which I have just named. Before further elaboration on the research design, let me note how the thesis engages with longstanding concerns in the academic study of religion.

1.2 The Thesis within the Field of Religious Studies

Stigma, discrimination, and abuse of PWA emerge from public perceptions, beliefs, rumours, and myths about albinism. In the 2000s, a belief that body-parts (e.g., limbs, head, genitals, tongue, blood, and bones) from a person – especially a child – with albinism can be used in potions or as charms to bring fortune and success spread across African countries. Consequently, hundreds of Africans with albinism have been mutilated and murdered, and thousands live in constant fear of being attacked. The macabre physical violence against PWA in Africa might be the most noticeable form of human rights violations. Equally alarming, many (if not most) persons with albinism face interpersonal violence from family members, classmates, teachers, and neighbours. Thus, beliefs of supernatural character together with socio-economic factors contribute to the problem of physical and psychological injuries to PWA. At the same time, I am interested in exploring the dangers of blaming witchcraft belief for the harmful practices against PWA and how to avoid contributing to colonial stereotypes of irrational Africans.

A second way this ethnographic account concerns itself with matters of interest to the study of religion is that the central person in the ethnography – one might indeed say the protagonist in the story – is a woman of profound Christian faith who frequently and eloquently speaks of her faith. The religiousness of Sr. Martha is especially noticeable when she talks about her trauma recovery and motivation to help others with albinism despite safety risks and financial challenges. Sr. Martha's work and the organisation Peacemakers for Albinism and Community rest on the religious conviction that God is the loving creator of all human beings and creatures. It helps her convey the message to communities that albinism neither is a curse nor a source for wealth. Moreover, another question that interests me is: what role does religion and spirituality have in the life of a traumatised person with albinism?

I think about the complex reality religion and spirituality play in the lives of PWA. Discriminatory behaviour and violence against PWA might be understood in part on religious grounds. At the same time, a person with albinism can find strength and purpose in sacred teachings to religiously cope with trauma and stress. How are we to understand this paradoxical role of religious belief when telling stories, doing research, and providing support to the albinism community? Both religious dimensions – the supernatural belief about albinism and the faith of a rather heroic woman to protect children with albinism – are illuminated in the ethnographic detail of this thesis.

1.3 Research Methods and Contributions

What fascinates me most in terms of theoretical exploration is a somewhat "meta" question: a question that involves taking a step back from the ethnographic material, from the lives and practices I have just mentioned. I am interested in exploring how best to tell a story about a humanitarian situation that will win the interest, sympathy, and engagement of persons outside the story setting. It leads me logically to explore storytelling strategies which give birth to the different ways I have chosen to engage the public to convey my message. One can say that the project's framework is storytelling with an additional focus on religious and ethical dimensions.

Like most ethnographers, I used methods of participation-observation, fieldnote writing and ethnographic interviewing to collect detailed research data from the albinism community in Arusha, Tanzania over seven months. Meanwhile, my ambition to raise public engagement for albinism span over 17 months.

Data collected, produced, and analysed are the following: (i) field observations and events as described in my field diary and notes, approximately 45 single-spaced pages; (ii) over 1500 photos and 90 videotapes from the field; (iii) 4 voice recordings; (iv) 47 posts published on my Facebook and Instagram accounts; (v) over 190 Instagram Stories and (vi) 4 types of responses from the public (i.e., social media interactions, donor giving, participating in events and buying an Albinism Awareness product).

The study, moreover, deliberates on the public actions that emerge as a response to digital storytelling, but also digital and physical events. Testimonies and stories from the field link to well-known global issues of discrimination and stigmatisation against PWA, reported and studied by other scholars and journalists.

1.3.1 Previous Research and Thesis Contributions

There has been a growing body of scholarly work on albinism since popular media began covering the rise of harmful attacks and deadly violence in the early 2000s. Much popular media addresses the horrific persecution. Researchers on the other hand, have focused on a wide variety of topics such as: attitudes (Masanja, Imori and Kaudunde, 2020), subjectivity (Brocco, 2016), religious beliefs (Benyah, 2017), childhood trauma (Aborisade, 2021), education (Lund, 2001), reactions for the birth of a baby with albinism (Taylor *et al.*, 2021), gender-based violence (Ojilere and Saleh, 2019) and objectification (Daniel Ikuomola, 2019). However, only a few, such as Schüle (2013), Oestigaard (2014) and Imafidon (2017), seek to explain the sudden increase in attacks by considering additional contributing factors more than witchcraft beliefs.

Relatively many studies conduct questionnaires or in-depth interviews with PWAs to assess how they are marginalised, and what the consequences are. Nonetheless, it appears to be less common for scholars to adopt ethnographic research methods and follow a person for an extended period whereby they would shed light on the width of challenges prevalent at many levels. The thesis contributes to the field of research by adding new and deepened perspectives on: (a) challenges and discrimination as experienced by a woman with albinism in Tanzania; (b) religious and spiritual dimensions in justifying, combating, and coping with violence against PWA, and (c) public responses and ethical dilemmas emerging from digital storytelling.

Fortunately, with the creation of a UN mandate for an Independent Expert on the enjoyment of human rights by persons with albinism in 2015, focus areas of research have also moved beyond African countries to assess human rights violations against PWA at a global level. The diversification is much welcomed as the issue of discrimination is not an isolated case for Africa. Still, there is an underrepresentation of other geographical settings and a knowledge gap in understanding levels of albinism awareness and how albinism affects individuals in more developed countries, such as Sweden. Although this thesis does not engage itself with the last-mentioned topic, it touches on albinism awareness when telling stories to engage the public. Furthermore, the responses showed by the public reflect to some extent general knowledge about albinism.

Surprisingly, despite the number of studies (and other work) on albinism, none addresses the ethical dilemmas of photographing PWA to raise awareness or funds. How to engage the public without the risk of exotifying individuals who already experience stigma, discrimination, and violence because of their appearance? The thesis brings attention to this dilemma which adds to the literature on moral leadership and communication strategies for humanitarian work and fundraising appeals.

1.3.2 Limitations

The thesis is a hybrid in the sense that it neither falls under the category of fully ethnographic nor conventional academic but combines the two. The insider's and outsider's perspectives are equally important for the thesis by providing both valuable insights on albinism and problematising concepts that grounds theory. At the same time, ethnographic findings are subjective and contextual which does not allow for generalisability. Notwithstanding, the thesis is considered to have a high level of representativity of challenges and discrimination faced by people with albinism in Tanzania as well as in other neighbouring countries.

The reader might find descriptions to be many and the narrative voice to be dominant, still, scenarios described are only a fraction of all data collected. If not for limited space several topics could have been expanded and further elaborated. The reason for bringing up a broad scope of different issues – from religious coping to discrimination and factors contributing to violence targeting PWA – is to highlight the complex situation facing the albinism community in Tanzania. There is a risk that the mere scraping of the surface of topics results in a lack of coherence.

The conceptualisation of "instrumentalising rumours" emerged from my need to avoid reinforcing colonial power structures by using the word "witchcraft beliefs". One should keep in mind that the linguistic reflection does not build on a concern raised by Sr. Martha or scholars. A thorough analysis would have taken other opinions of various agents into account. In addition, it is possible that using instrumentalising rumours will not result in a more holistic approach to tackle issues of stigma and violence against PWA. And most certainly, one might say that suggesting the usage of a new term itself, reflects uneven power structures.

1.4 Structure of the Thesis

The written product of an ethnography is crucial and the reason for the many descriptions and narratives found in this thesis. It is also why the paper's structure is rather unique with integrated chapters (i.e., theory and method, literature review and findings) that normally stand on their own in a master thesis. Regarding this I found it necessary to explain how the paper is structured.

Inspired by the book *The Twilight of Cutting*, written by anthropologist Saida Hodzic (2016), each chapter in this thesis begins with a narrative, description, or dialogue – a so called "opening vignette" (Kwame Harrison, 2018b:17) – from the field that represents the topic of a chapter or sub-section. The thesis consists of six chapters.

Chapter 1 introduces the research topic and presents the scope, purpose, and contributions of the thesis. Research methods and theories used to collect and analyse data are integrated into Chapter 2. The study's research design has been placed before the literature review to give a thorough explanation to the structure and literary format of the thesis.

Chapter 3 gives a background about the occurrence and frequency of albinism, thus lays a foundation for the aim and purpose of the thesis. The chapter brings up global discrimination against people with albinism from a human rights perspective and further describes the persecution of PWA in African countries with a focus on Tanzania. Topics brought up in the literature review tie into ethnographic observations and narratives from the field work throughout the chapter.

The juxtaposed roles of religion and spirituality in contributing and combating violence against people with albinism are further studied in Chapter 4. This chapter discusses driving factors that motivate and justify harmful practices. By outlining the diverse religious landscape in Tanzania and discussing the problem of explaining attacks and violence because of witchcraft beliefs, I argue for the invention and usage of a more inclusive term as mentioned above: instrumentalising rumours. One could say that Chapter 4 takes a step back from the individual aspects of the research question by focusing on how deadly violence against PWA, generally is portrayed and understood in media and by scholars. What are the implications of such portrayals?

Chapter 5 revolves around the research question: how does one tell a story about people with albinism that will engage the western public without diminishing their dignity or violating ethical standards? I give an overview of the ways I have engaged the public about albinism and the responses these activities led to. I present theories on donor giving and evaluate how I tackled ethical dilemmas regarding fundraising appeals and humanitarian photography.

Finally, the study's findings are summarised, and the research question is addressed in Chapter 6, accompanied by suggestions for future research on the topic. I suggest a comparative analysis of ethical standards that consider journalistic, academic, and artistic (e.g., photography) work from different organisations and instances to ask: what range of portrayals might be considered unacceptable? The development of a decision tree could further help in exploring different cultural contexts and what kind of portrayal might be experienced as diminishing someone's dignity.

Chapter 2. Research Design

During one of our interviews, I ask Sr. Martha a tough question, because how else am I to explain her engagement for children with albinism despite challenges she faces? The voice recorder is on, my notes in front of me and my arms lifted as I also record the interview with my phone to make a video. I ask the question: “Would it not be easier for you and Edmund [Martha’s husband] to not shelter the children?” (From an interview with Sr. Martha, January 7, 2022).

In this chapter I present the study’s design, methodology and theoretical stands. It is worth noting that there is often a limited role of theory in ethnography since the purpose is often to describe cultural behaviour and social actions rather than testing a certain theory based on a hypothesis. Positivistic, social science researcher often presents a single argument or theoretical claim throughout a whole work. Ethnographies, by contrast, often contain several small theoretical explorations, none of which is necessary dominant in the work. In other words, ethnographers value vivid description as itself a contribution to knowledge. Therefore, I integrate research methods and theoretical standpoints into one chapter (2). However, in Chapters 3 and 5, I discuss ethnographic observations by referring to theories on religious and spiritual coping (Gall and Guirguis-Younger, 2013) and donor behaviour when presenting my experiences of engaging the public (see Shier and Handy, 2012; van Rijn, Barham and Sundaram-Stukel, 2017; Carvalho, Hildebrand and Sen, 2019; Septianto and Paramita, 2021).

2.1 Ethnography

I stay in Tanzania for six months during the second research phase. Sr. Martha is often busy – attending meetings, participating in workshops, visiting schools – but always ready to postpone activities or re-schedule meetings if someone is, what she would describe as, “being stranded”. Like the good Samaritan, she gives a helping hand to everyone regardless of their differences and difficulties, be it a child with albinism or a child to a mother with albinism.

An important dimension of ethnography is the creation and management of observations through field-note writing and formal and informal interviewing (Kwame Harrison, 2018a;19). By noting settings, dialogues, characteristics and events, the researcher creates and collects data. Thick description[6] – in the opinion of Geertz (1973) – is the mission of ethnography: to describe cultural life and social actions with rich and telling details. Hammersley (2008, cited in Kwame Harrison, 2018b:23) refers to this as an adverbial mode of writing which the professor and author Kwame Harrison explains in the following way:

> Whereas one can get away with saying, "She walked in the room looking tired," the ethnographer aspire to explain what type of tired – tired from having run 200 meters or tired from having waited in the line at the hospital all day? – as well as what it was about the way she walked into the room that conveyed this: Was it her breathing, perspiration, posture or the look on her face? (Kwame Harrison 2018b:23)

Although ethnographic methods frequently are adopted into qualitative as well as quantitative research, ethnography is not just adding distinct qualities to research methods but is a research and writing tradition on its own (Kwame Harrison, 2018a:16). Thus, according to Harrison (2018a), ethnography describes a methodology and produce ethnographies (e.g., written products; books, essays, journal articles as well as non-literary forms, Kwame Harrison, 2018a:4;5;27). Subsequently, the objective of ethnographers is not so much to test a theory but to portray in detail and reflect upon a particular milieu of people and their interactions. In contrast to conventional processes of conducting research, ethnography does not build on a hypothesis since doing so would require the researcher's pre-assumptions about research subjects which risks overriding the native's point of view. Another core practice and goal of ethnography is to represent both insider and outsider perspectives and is achieved through participant-observation (Kwame Harrison, 2018a;17).

I have chosen not to present findings and analysis in just one chapter. The reason is that research data consist of vivid narratives, and at the core of ethnography lies its written product. Therefore, it does not make sense to dedicate solely one chapter to detailed descriptions, but instead to alternate these with excerpts from my field diary and theoretical reflections throughout this ethnographic thesis. One can say that each chapter contains findings and an analysis with theoretical reflections that makes a chapter resemble a minor paper. As Harrison (2018b) explains the difference between conventional research reports and ethnographies:

---

[6] Coined by Ryle (1971, cited in Geertz, 1973:6).

> Ethnographies embrace literary approaches, which involve presenting the research as an unfolding series of examples, episodes, observations, contextual/informational insights, and epiphanies. Good ethnographic writing, therefore, involves cobbling various data and utilizing different modes of representation in such way that they hang together through a sense of narrative coherence. (Kwame Harrison, 2018b:6)

2.2 Research Data and Data Analysis

The first meeting with Sr. Martha in May 2021 touched me deeply because it became apparent that I knew little about albinism and was unaware of the daily threats people with albinism face – the sun being a major threat to their health and life. I wrote a post about our conversation and the difficulty for Sr. Martha to provide sun protecting means to all children with albinism. A reader commented on the Facebook post and suggested that I collected funds from my social media followers to support Sr. Martha. My first digital fundraising campaign had been born (see Román, 2021b).

Social media have been my main platform to raise albinism awareness. In addition to this, the three fundraising campaigns I have initiated have been online. I have spread information, engaged the public and collected funds in the digital sphere for two reasons. First, most people with access to digital technology spend a great amount of their time on the Internet, be it for studies, job meetings or to keep contact with friends and loved ones. Second, digital tools are an accessible and effective way to engage with people. I have created a total of 190 Instagram Stories[7] on different topics related to my ambition to raise albinism awareness since early May 2021. High quality pictures with descriptive stories from the field suited the Instagram Feed and Facebook, hence I have published 47 posts (text and photo) on the two social media platforms. These posts have received a total of 1,366 likes and 217 comments. Posts published on Facebook have been shared 46 times (See Appendix A, Table A1[8] for a comprehensive summary of total social media responses).

---

[7] The Story function allows social media users to upload pictures and videos that only will be available to the audience/followers (selected or public) for 24 hours. This form of storytelling welcomes social media users/followers to interact with the Story content as the narrator can attach polls, questionnaires, etc., to the Instagram Stories. However, Instagram users can highlight stories of their choice, which means that these stories can be re-watched by followers or other users, given that the highlight exists.

[8] References to figures or images where the number is preceded by a letter are found in the appendix corresponding to that letter.

I have not only limited my activities to social media platforms but held a webinar about albinism in June 2022. The online event allowed Sr. Martha to also join and virtually meet people who had supported her in various ways. Part of the webinar was a screening of a short documentary I made about Sr. Martha's engagement and Christmas celebrations. I have also shown the documentary in an event for young people at the Uppsala City Library and in two classes at Uppsala University. These movie screenings sparked discussions about digital storytelling and questions from the audience to learn about albinism and Sr. Martha's efforts to shelter CWA.

From late August to mid-October 2022, I exhibited 10 photos from my time in Tanzania at the restaurant Don Felice in Stockholm. The photos have been carefully chosen and a short story next to the frame gives the reader a deepened background to the work of Sr. Martha. Table A1 summarises the six ways I talked about albinism to engage the public: (1) Instagram Stories; (2) Instagram posts; (3) Facebook posts; (4) photo exhibition; (5) public lectures and (6) one webinar. These different ways of telling a story have led to four categories of responses – (A) social media interactions; (B) donor giving; (C) participating in an event and (D) buying an Albinism Awareness product.

It is here relevant to present how the research material has been organised, sorted, and analysed as it might differ from more formal and positivistic traditions of conducting research. Ethnographers start to analyse cultural practises and behaviour as soon as they start taking field notes as part of the writing process. To one more time cite Harrison (2018:b:2), "through their constant writing ethnographer are continually documenting, making sense of, and characterizing social phenomena". Further, there are two ways of approaching the data and writing up research findings, (1) the organisational approach and (b) the evocative approach – I have tried to use both. The former favours empirical precision, whilst the latter focuses on the importance of the authorial role to connect with the readers (Kwame Harrison, 2018b:6).

Moreover, the paper's structure reflects how research data has been organised into themes and topics with illustrative examples and "supplement information" (Kwame Harrison, 2018b:7). I have identified and categorised data into three major themes (1) human rights violations against PWA; (2) instrumentalising rumours and (3) ethical dilemmas arising when telling stories to engage the public. These themes have been assigned one chapter each and emerged through what Harrison (2018b:9) refers to as "experiential-intuitive understanding" and "methodically revisiting". Similar for these chapters is their biographical approach, where I discuss topics at a broad level before narrowing in down to specific experiences and cases. Other themes that emerged when revisiting my field diary are: (a) challenges of doing ethnographic work (reflexing my emotions and thoughts), (b) discrimination because of albinism and (c) specific events or scenarios observed.

2.3 Reliability and Representativity

During one of our many conversations, it becomes apparent that Sr. Martha wishes to start a new sewing group to provide capacity-building to young adults with albinism. I cannot hide my excitement, but tell her about the make-up bags and coin purses I have sown and sold in Sweden to raise albinism awareness and support PAC. What if the women with albinism could be taught to sew those? During the two following months I learn how to use a tramp sewing machine together with four women with albinism before I begin to teach them how to sew coin purses.

Research data collected and analysed is subjective because of my participation in the albinism movement and growing compassion for Sr. Martha with a desire to sustain her work for CWA. Once back in Sweden (May 2021) I adopted entrepreneurial tools to increase the funds further by creating and selling tote bags. Some with a positivistic view of science might criticise my involvement as biased, threatening the study's reliability. Instead, by showing my interactions with research subjects, the reader will see how the knowledge presented in the thesis emerged (Kwame Harrison, 2018b:4). The goal of the thesis is not to create standardised data ideal for comparison and generalisations but to shed light on the life situation of people with albinism by focusing on the life story of one rather heroic person, Sr. Martha. It is not uncommon for an ethnographer to observe only one person. For instance, anthropologist Michael Herzfeld wrote the book *Portrait of a Greek Imagination* (1998) based on his intellectual relationship with the Greek novelist Andreas Nenedakis.

My involvement – as a researcher – with the research subject is not a threat to the study's reliability, but rather a necessity that builds social intimacy. Indeed, the ethnographer is by Fetterman (2010:33) perceived as a human instrument for data collection: "Relying on all its senses, thoughts, and feelings, the human instrument is a most sensitive and perceptive data-gathering tool".

As such, I believe my engagement has been essential to building trust and rapport between me – the researcher – and Sr. Martha – the researched – that yielded the detailed-rich data the thesis seeks for. In addition to this, my participation in the women's sewing group can further be seen as Participatory Action Research or what professor and ethnographer Lane (2022) coined as "workalongs".

2.4 Ethical Responsibility and Good Research Practice

If a researcher's involvement raises questions about reliability and validity, then non-involvement should equally lead to questions regarding moral dilemmas and responsibility towards the researched, not least if conducting studies in foreign countries and targeting marginalised respondents for data collection. For whom do you conduct a study? To advance your career? To make a social change? What are the accountabilities of researchers? Not acting after interviewing Sr. Martha and realising the challenges she and PAC face would have left me with a feeling of guilt. Ultimately, I would be exploiting my respondent and ignoring the trust she put in me when giving her consent to be part of the study. Therefore, as much as this study is about storytelling, raising awareness about human rights violations, and analysing donor giving and other solidarity, it reflects on the role and accountability of the researcher and how she leaves the field. Researchers have obligations, which the author and child psychiatrist Robert Coles reminds us about with a very important question:

> What are one's obligations not to oneself, one's careers, the academic world, or the world of readers, but to the people who are, after all, slowly becoming not only one's "sources" or "contacts" or "informants", but one's graciously tolerant and open-hand teachers and friends – *there* – week after week, with answers to questions, with hands ready to pick up crayons, with the courtesy and hospitality of food and drink, with advice, with revealing second thoughts to discussions one had long ago put aside, but most important, *there* in their available yet so vulnerable and hard-pressed and precarious lives? (Coles, 1997)

I contemplate whether Sr. Martha's identity in the published material from the ethnographic observations should be protected? After all, she shelters children with albinism for their safety but without the advanced home security one would want and expect. She cannot afford to buy a guard dog or pay the salary of a night watchperson. I wondered how she can ensure their safety and with great assurance she tells me that they rely on "the grace of God".

Undoubtedly, their safety is a fragile construction and I decide to not describe their home or post photos that can reveal where it is located. The time I visit her at home, I travel with the same taxi-driver whom we both trust.

Eventually, Sr. Martha and I, arrive at the decision to not use a pseudonym for Sr. Martha as the purpose of the thesis is to shed light on her lived experiences, altruism and work to raise albinism awareness and public engagement. For the same reason it is not hidden that Sr. Martha and PAC operates in Arusha which additionally is stated on the website of PAC and the reason for how I met Sr. Martha. Meanwhile, the identity and integrity of children are not exposed in the thesis or on digital platforms. Firstly, the children are not considered research subjects. Secondly, their identity is not revealed to protect their safety and respect their integrity and dignity. An exception from this ethical position has been made with regards to the photo exhibition showing my ethnographic work. A more detailed discussion and motivation for this decision can be found in Chapter 5.

It is relevant to mention that Sr. Martha has not signed a Letter of Consent for two reasons. Firstly, such formalities could strain the relationship-building that ideally forms with friendship, mutual trust, and respect. Secondly, asking someone to sign a consent form could sometimes put the signer in a weaker position unless they are familiar with academics and with relevant laws. If not, a consent form risks emphasising differences in educational experiences that could discourage or disempower the respondent.

I told Sr. Martha about my idea to conduct an ethnographic field study about her life and work one day in November 2021. We met at the local café Kitamu, later that day I wrote in my field diary:

> I explained the purpose of ethnographic studies and why I thought [observing] Sr. Martha mattered. Did I talk too loudly because the café was crowded? Would people think I am taking advantage of Sr. Martha because of her albinism? However, Sr. Martha agreed to be part of the study but said: “I don’t know if I can explain much to you”.

2.4.1 Being an “Outsider” and Cultural Appropriation

Before further elaborating on my background and positionality as a student and researcher, I want to briefly touch on the ethical dilemmas of ethnography and the topic of "cultural appropriation". I aspire to explain why I do not consider the thesis to be a case of the latter.

Ethnography (like most scientific disciplines) has often contributed to Ethnocentrism. More to the point, ethnographic contributions often associate with observations made by explorers or the "outsider" under the practice of colonisation. Today, ethnographers tend to be aware of their discipline's history and the critical discussions around it. Subsequently, some ethnographers choose to conduct their study within their own community while others seek to observe the daily practices and behaviour of another culture. In doing so, the ethnographer often stays in the field for an extended period (not seldom for years), learns the native language and participates in all kinds of activities to capture the nuances of the culture, and not least, to build trust with the host community. Some might criticise the work of an outsider ethnographer because – how accurate can the cultural representation possibly be if written by an outsider? Meanwhile, most anthropologists and other ethnographers agree that an outsider can capture nuances of cultural aspects that the insider might not "see" by being too familiar with the setting. The anthropologists John Monaghan and Peter Just write:

> While the insider is capable of noticing subtle local variations, the outsider is far more likely to notice the tacit understandings that local people take for granted as "common sense" or "natural" categories of thought. The outsider status of the ethnographer, then, can be regarded as a strength as well as a weakness, even as a strength crucial to the success of the enterprise. (Monaghan and Just, 2000:30)

The ethical dilemmas of ethnographic fieldwork and the debate on whether the ethnographer should be an insider or outsider ties into the topic of cultural appropriation. Whose story can I write?

Cultural appropriation is a term that refers to "taking someone else's culture – intellectual property, artefacts, style, an art form, etc. – without permission" (Manigault-Bryant cited in Morton, 2020). Several public figures have been accused of cultural appropriation in recent years, such as Kim Kardashian, Elvis Presley, and Amanda Lind (former Minister of Culture of Sweden). Undoubtedly, there have been cases where people have used cultural symbols and clothing in disrespectful manners – seldom being aware of their cultural significance for minority groups and indigenous people who often were forbidden to practice their culture. The debate on cultural appropriation has reached a point where authors equally could be questioned for not "staying in their line" (Morton, 2020), hence writing about others (who belong to groups which the author does not identify with). At the same time, one should not forget that art (telling a story is an art) also bears the potential to express empathy with others. In a comment, artist Dana Schutz met some of the critiques she received for her painting of Emmett Till in his open casket. The British artist Hanna Black, based in Berlin, demanded the painting to be destroyed. Schultz wrote:

> I don't know what it is like to be black in America, but I do know what it is like to be a mother […] My engagement with this image was through the empathy with his mother… Art can be a space for empathy, a vehicle for connection. I don't believe that people can ever really know what it is like to be someone else (I will never know the fear that black parents may have) but neither are we all completely unknowable. (Schutz cited in Morton, 2020)

I believe that a written product – be it scientific, fictional, or non-fictional – carries the potential for writers to express and show empathy. Undoubtedly, as an author, you must be honest and ask yourself why you are telling the stories of others. Do you do it in solidarity with people to shed light on their reality, or do you steal their stories to put yourself in a good light?

The danger of "Stay in your lane" (Morton, 2020) is that stories will be untold. In addition, we risk reinforcing the politics of "Otherness".

I hope you will find that the protagonist of this thesis is Sr. Martha together with those who have engaged with her work. It is thus not about me, even though my voice is present in first-person writing. When we read about the lives of others, we imagine a life different or similar to ours. We become aware of situations we otherwise might not know about, or we find that someone shares our experience and emotions. The American writer Brian Morton (2020) argues that "imagining the lives of others is an essential part of the effort to bring into being a more human world". I hope the thesis will invite you to imagine the lives of people with albinism.

2.5 My Background and Positionality Within the Study

Carrying out an ethnographic study is not an easy task to undertake. I have questioned the project and whether it will create new, scientific knowledge or not. In the field, I found myself frustrated because I was impatient and wanted to start observing and participating in the life of Sr. Martha as soon as possible. Meanwhile, Sr. Martha carried on with her work and daily activities; she took her time to get to know me and my intentions (who was I to think she would set everything on pause for my sake?). When we met, we did so at the café Kitamu or her office. Nine months after seeing Sr. Martha for the first time, on the 21st of December (2021), I received an invite to her home. I remember this as a significant turning point in the project as I now would be able to do proper participant observation.

In the paragraphs that follow, I reflect on my background and positionality as a student and outsider and what implications these might have had on Sr. Martha and other people I met during the fieldwork.

I travelled to Tanzania for the first time in 2015 as a volunteer. I began questioning the definition of "development" and my participation in "voluntourism" and white saviorism. Today, I feel ashamed of the naïve and Eurocentric worldview I held at the time. For instance, that I, as a twenty-year-old woman, would contribute – with exactly what? – to an orphanage, because it was in Africa.

On the other hand, I doubt that I would question hierarchical power structures in north-south relationships and development approaches if it was not for that experience. Since then, I have tried to let go of my presumptions about Africa and perceive it as the rich and diverse continent it is. My Swahili knowledge is at the lower-intermediate level, enough for small talks, but my ambition is to reach the advanced level. It is important for me to learn the national language of Tanzania to interact with people and to show my respect as a foreigner. I lived in Tanzania for one year during my master studies. In addition to this, I have done an internship at a women's rights organisation in Nairobi 2019 (Kenya) and conducted a minor field study in the same city the following year.

Even though I try to be as open as possible in the field, my positionality, hence my gender, age, background, and occupation affect the people I meet and how they perceive me. Perhaps they respond in specific ways because they assume that it is an answer I would like to hear. However, since the study's main activities have not been to conduct many interviews with various respondents or moderate focus groups discussion, my position has probably had a limited influence on the individuals who I observed.

I would like to end this chapter with Sr. Martha's answer to a question asked by my supervisor Brian Palmer, during the webinar on 19 June 2022.

- Martha, I wonder if you could describe for us, how you first met Linnéa – how did she arrive on the scene from this distant northern country? What was the first communication and the first meeting like?

- Oh, the first time to meet Linnéa, she really came as just a person who just come to our place [the office]. [She] was very polite […] Her questions were very friendly; she did not even show that maybe she is very [highly educated].

Chapter 3. Albinism

Sr. Martha was born in 1963 in northern Tanzania as the fifth child, but the first one with albinism. Her parents cared for her, but the environment where she grew up was harsh; she faced stigma and had no friends except her mother. During an interview in January 2022 Sr. Martha tells me:

> I have tested all the hard situations in my life. Almost all. If to be neglected. To be not accepted from my relatives, from school, even the teacher did not accept me. So, I grew [up] in a hard situation. I reached even to a point to commit suicide or to kill myself. (Interview with Sr. Martha, January 7, 2022)

3.1 Causes and Frequency of Albinism

Albinism is a visible genetically inherited condition and exists amongst all living creatures: humans, animals, and plants. Albinism is caused by a genetic mutilation – leading to partial or total absence of melanin in humans and animals and chlorophyll in plants. Melanin is a pigment produced by cells called Melanocyte found in the skin, hair, and eyes. The more melanin produced, the darker skin, hair and eyes will get. Oculocutaneous albinism (OCA) – affects the production of melanin in eyes, hair, as well as skin – whilst some types of ocular albinism (OA) only affect an individual's eyes. The affected being whose melanin production is not functioning gets a distinguished outer appearance with pale skin, yellow and white hair and reddish, violet, blue, brown, or grey eyes. The eyes appear reddish and violet because of lighting conditions that show blood vessels in the back of the eye (Ero, Muscati and Annamanthadoo, 2021).

Both OCA and OA are inherited in an autosomal recessive inheritance pattern, meaning that both parents are carriers of the mutilated gene. The offspring must get two copies of the gene to have the condition albinism (NHS, 2020). Thus, parents who carry the mutilated gene but are not having albinism themselves "have a 25% chance of having an unaffected child… 50% chance of having an unaffected child who also is a carrier [of the mutilated gene] and a 25% chance of having an affected child" (Mayo Clinic; see Figure B1). This is the reason why parents without albinism can give birth to both children with and without albinism, as in the case with Sr. Martha´s parents. The inheritance pattern resembles how sickle cell anaemia and cystic fibrosis is passed on (Genetic Alliance, 2009). Another less common form of albinism, Hermansky-Pudlak Syndrome, affects eyes, hair as well as the skin and includes blood clotting problems and in some cases, pulmonary fibrosis (MedlinePlus, 2022).

OCA is the most common and (in most countries) visible form of albinism. Because the lack of melanin in skin and eyes, albinism leads to two health concerns: (1) visual impairment and (2) increased risk for skin cancer due to skin damage from the sun's ultraviolet rays (Ero, Muscati and Annamanthadoo, 2021:2).

There is a lack of reliable statistics on the prevalence of albinism globally and regionally. Most cited sources suggest that the frequency of albinism is 1 in 20,000 in Europe and North America which often gets compared with the frequency of 1 in 5,000 to 15,000 in Africa. Reports estimate that 1 out of 160 individuals of the indigenous people in Panama has albinism, and 1 in 7,900 to 27,000 in Japan. However, recent findings suggest a higher frequency of albinism than previously thought in western countries, with 1 in 12,000 in the Netherlands and 1 in 4,500-6,600 in Ireland (Krujit, et al., 2018 cited in Ero, Muscati and Annamanthadoo, 2021:12).

It is possible that people with OA might not be aware of their condition as albinism. The same goes for people with OCA who live in countries where most of the population is pale. In contrast, albinism is a highly noticeable condition in communities where dark skin pigmentation is common. No matter their ethnicity, people with OCA get light to pinkish skin, white or yellow hair and grey eyes.

It is the first time we meet at the café Kitamu (November 2021). We talk for a long. The waitress comes up and asks for our orders two times before I tell her that I will come down to the counter and order. It is not until then I realise that Sr. Martha has not even opened the menu placed in front of her, I ask if she needs help to read, she replies: "Yes, the text is too small".

Albinism often results in poor vision. Dr. Patricia Lund writes: "Lack of melanin also results in abnormalities of the visual pathway, leading to lifelong ocular problems that are always associated with albinism, including photophobia, nystagmus, lack of stereopsis, reduced visual acuity and often strabismus and large refractive errors" (Lund, 2001:1). Since 2008, the Convention on the Rights of Persons with Disabilities considers people with albinism as people with disabilities because of their visual impairment (Ero, Muscati and Annamanthadoo, 2021:8-9). With this acknowledgement, PWA are right-holders and should not be discriminated against their education or employment because of their disability.

The report People With Albinism Worldwide (Ero, Muscati and Annamanthadoo, 2021) eloquently categories common types of global discrimination because of colouring and visual impairment as violations against five human rights: (1) right to education; (2) right to work and adequate standard of living and (3) right to health; (4) access to justice and (5) right to life. Following sections explain the consequences of various types of discrimination and increase the understanding by providing descriptions and narratives from the ethnographic case study in Tanzania.

3.2 Discrimination

- What is your hobby?

It is the first time she addresses me. A bit surprised with her forwardness I reply:

- I like drawing and working out, what about you?
- I play football. Back in school I would play a lot.
- That’s nice. Do you have any place where you can play here in Arusha?
- No.
- But what about Moshono? There must be a place where you can play?

She tells me she cannot. Why? – Because of her condition. She says her neighbours are afraid of her. Some believe she cannot play; others fear she will cause them bad luck if they touch her. She only plays football when in boarding school. People there are aware of albinism and neither believe it is contagious nor that body parts cut off from her possess magical powers (from field diary, 17 February 2022).

People with albinism across the globe, face stigma, discrimination, and even violence because of their appearance. Scholars, journalists, and victims have testified that negative attitudes, stigmatisation, and harmful practices against PWA, like discrimination against disabled people, are caused by myths, beliefs, and superstition. Common-held myths include that albinism is a contagious disease and that PWA cannot complete tasks – mental and physical – as others (Masanja, Imori and Kaudunde, 2020:527; Ero, Muscati and Annamanthadoo, 2021).

Another known myth is that the birth of a child with albinism is a curse (Smith, 2008; Brocco, 2016; Ero, Muscati and Annamanthadoo, 2021), misfortune or punishment (Benyah, 2017:168) for past mistakes of parents or ancestors. As such, children and adults with albinism are not perceived as humans (Benyah, 2017:177), but as ghosts or spirit beings (Taylor, 2015; Imafidon, 2017), who do not die but disappear. Not seldom are mothers who gave birth to a child accused of sexual infidelity with a white man (Engstrand-Neacsu, 2009; Schüle, 2013;

Oestigaard, 2014:184). For this reason, but also in combination with other deep-rooted myths and lack of understanding, fathers often abandon mothers and CWA. Village-member might stigmatise, exclude, or even chase the mother and child away if the child is not killed (Schüle, 2013:8; Brocco, 2016; Benyah, 2017; Masanja, Imori and Kaudunde, 2020; Ero, Muscati and Annamanthadoo, 2021). Rumours say that intercourse with a woman with albinism will cure HIV/AIDS. Consequently, women and girls with albinism sometimes get raped and may contract the fatal virus (Gipson, 2014; Oestigaard, 2014; Ero, Muscati and Annamanthadoo, 2021).

Along with the myth that albinism is a curse is another contrasting myth and belief: that body parts from a person – especially a child – with albinism are a source of good fortune. Fishermen, miners, politicians, and others have sought counsel from traditional healers in their quest for success and wealth, at times advised to return with hair, nails, blood, or specific body parts from a person with albinism to be used in rituals, potions, and charms (Smith, 2008; BBC, 2009; Wanjiru, 2010; Dghar, 2022). Children are sometimes kidnapped. And both children and adults have been attacked by men with machetes while sleeping, eating, or walking home from school. Victims have died from injuries or been forced to adapt to a life without their limbs. The most recent reported murder took place in late April 2022 in Mozambique (Club of Mozambique, 2022). Graves are sometimes desecrated, and robbers have chopped off limbs from deceased PWA (York, 2010). A grave of a 35-year-old person with albinism in Malawi was desecrated in July 2022 (AAN, 2022).

Needed to say, major progress has been made since the peak in attacks and killings of PWAs in the late 2000s. For instance, hundreds of NGOs on the African continent support people with albinism. Beauty pageants for PWAs have been held in several African countries since 2016 (New York Times, 2018; Tato, 2018; Manaleng, 2021). The latest to be crowned Miss Albinism was the Zimbabwean Angela Nokuthaba Dube (Chronicle, 2022). And in August 2022, Martin Wanyonyi became the first elected MP with albinism in Kenya (Whowns Kenya, 2022). The Malian singer Salif Keita and the Malawian musician Lazarus Chigwandali are both singing out loud to raise albinism awareness (Savage, 2019; People With Albinism, 2022). Without any doubt, the creation of the UN mandate for an Independent Expert on the enjoyment of human rights by persons with albinism in 2015 has brought albinism to the agenda of human rights advocates. However, despite positive signs of progress, discrimination and violence remain widespread.

3.2.1 Education

Sr. Martha introduces me to twins with albinism she has supported since childhood, and now they are in their late teenage years. One afternoon, one of the twins tells me that some of her teachers are mean. She explains how they demand her to complete her notetaking when her classmates have finished. But she cannot because her vision is not that good, so it takes time. It reached a point when she could not bear the unfair treatment and took off to the headmaster's office to inform him about albinism and visual impairment. She hoped all teachers would grant her more time to complete tasks (based on an informal conversation with a teenager with albinism, February 2022).

Various reasons might keep parents from sending their child with albinism to school, be it financial or social. Some assume the disability makes the child incapable of succeeding or that school is a waste of money given the shorter life expectancy for PWA. Others cannot cover the school expenses or keep the child at home to hide them, perhaps due to social stigma, fear of violent attacks or sun exposure.

Sr. Martha was unable to read what had been written on the blackboard from the very end of the classroom and her grades shrunk beyond the entry-requirements for secondary school. The teachers had placed her by the end because they thought albinism was contagious. Similarly, children with albinism in India have been rejected school admission from school authorities because of other parent's misbelief that albinism is contagious (Ero, Muscati and Annamanthadoo, 2021:55). Japanese students were until recently forced to dye their hair black to enrol in school (Ero, Muscati and Annamanthadoo, 2021:21;56).

In the case the child gets to school, new barriers lay ahead. The process to receive reasonable accommodation (e.g., adaptive learning devices, more time to complete task., etc.,) is often long and the legislation complicated even when children by law are obliged to receive help and support. Schools and teachers in less advanced states often fail to provide adequate support and assistance to students with albinism because of a lack of knowledge and awareness. In a study conducted by Lund, (2001) in Zimbabwe, 96,6% of 138 schoolchildren with albinism stated that they were "unable to see the blackboard or print in text books because of poor vision" (Lund, 2001:2).

In March 2022, Sr. Martha tells me about a phone call with a mother whose children get awful sunburns in school because the teacher will not let them wear protective clothes: "Everyone must wear the school uniform", says the teacher. After several attempts to inform the teacher, the mother reached out to Sr. Martha in desperation. I sense a bit of frustration and exhaustion in Sr. Martha’s voice when she tells me about the call she must make to the school. Perhaps it drains her that actions on something so elementary as protective clothing, are still needed in 2022?

Students with albinism struggle to keep at pace with their peers due to their visual impairment and are falsely judged to be intellectually disabled with less ability to complete mental (but also physical) tasks (Masanja, Imori and Kaudunde, 2020:527; Ero, Muscati and Annamanthadoo, 2021). Children and students in Burundi, Côte d’Ivoire, Guatemala, Pakistan and India experience physical violence, bullying or isolation in school (Ero, Muscati and Annamanthadoo, 2021:55).

In Harry Freeland’s touching documentary *In the Shadow of the Sun* (2012) we get to meet the Tanzanian teenager Vedastus who stopped going to school due to mistreatment even though all he wants to do is to study. He draws computers on his wall, builds a TV out of cardboard and as a self-taught electrician makes sure the only lamp in the house is working. In the film, Vedastus is sitting on the floor of soil in his mother’s house. Mud under his barefooted toenails. His lips are sunburnt to the extent that it causes wounds, knees crawled up to his chin. It looks like tears fill-up behind Vedastus’ eyes which wander its gaze between the floor and into the camera, and he tells:

> Wherever I go, they say, “Look, the uncooked rice just walked by”. I don’t mind, I just walk on. Others just insult me. They abuse me. They find sticks to beat me with. So, I run off. When I line up for school, they remove me. They push me out. I just leave them alone and go to another line. When I get pushed from that line as well, I just go home, but they chase me to beat me up. I just try to run away. But they wait to get me the next day. (Vedastus, *In the Shadow of the Sun*, 2012:09:59-11:31)

High dropout rates and low school attendance reflect a discouragement amongst children and teenagers to complete their studies (Ero, Muscati and Annamanthadoo, 2021:58). The report on People With Albinism Worldwide states that in Zambia “people with albinism have a literacy rate of 66% compared to the national average of 92%, and only half of the population with albinism complete an education level greater than primary school” (Ero, Muscati and Annamanthadoo, 2021:59).

3.2.2 Employment and Standard of Living

The difficulties to access education for CWA drastically reduces opportunities to earn a degree with the benefit of working indoors and in the formal sector. Because of their appearance, visual impairment and socially held misbeliefs, PWA face additional barriers to get employed or build a base of customers even when they have succeeded in completing their education.

In several African countries it is believed that employing a person with albinism in the food and hospitality industries will negatively affect the company's reputation. A respondent from Ghana said: "Many employers shun from engaging PWAs to work in their company with the reason that they do not have the capacity to perform and also they may scare away potential customers" (Ero, Muscati and Annamanthadoo, 2021:69). Individuals with albinism in less developed countries are often forced to earn a living as manual labourers or subsistence farmers. Many struggle to acquire decent living standards and provide for their families. During my fieldwork I met some children without albinism whom Sr. Martha sheltered because their mothers with albinism cannot sustain themselves.

I am not comfortable asking Sr. Martha about her financial situation until a few months have passed. Before the Covid-19 pandemic, Sr. Martha used to have a monthly salary of 260 USD, today she earns a salary of 129 USD[9]. The reason is a loss of donations from foreigners or "compassionate friends living abroad" as she describes them. The salary is paid by the international NGO, Lahash, which bases on Christian values and partners with local ministries in four East African countries. Through the Lahash sponsorship program, 56 of the 96 children with albinism in PAC are sponsored, meaning that their school fees and school essentials are covered. Sr. Martha tells me about her financial situation, how she and her husband Edmund struggle to meet their needs. After paying her bills (electricity, water, charcoal, salary to the house girl) they are left with 43 USD for food that should last four weeks; "It is impossible", tells Sr. Martha. From time-to-time they loan 215 USD, but to receive the loan, they first need to pay 108 USD.

One day in January 2022, Sr. Martha opens a cabinet and takes out tailored sunhats and aprons made from African fabric. She starts telling me about a sewing group she started which

---

[9] This is below the lowest average monthly salary of 137 USD in Tanzania. As of 2022, the median monthly salary in Tanzania is estimated to 560 USD, and the highest to 2,400 USD (converted July 8, 2022, numbers taken from AjiraLeo, 2022; Salary Explorer, 2022).

consisted of marginalised women, women with a relative with albinism or women who cared for PWA. For every item sold, the tailors kept 90% of the profit, and gave 10% to PAC.

Sr. Martha supported the group with sewing machines and made sure they received training. Later, she advertised for their products as she met tourists or travelled the country to inform about albinism. She frequently (with the exception during the Covid19-pandemic) welcomes tourists to visit her office to receive information about albinism and her work with PAC. Most tourists feel inspired to help the continuation of her work by purchasing a product sown by the women, or supporting PAC in other ways (e.g., through projects).

However, due to unfortunate circumstances, the female tailors decided to split up and leave PAC. It was a big loss for the organisation (the women's group had profits of 5,574 USD from time to time) and a sad ending to Sr. Martha's relationship with the women she had helped. I sense disappointment, but mostly sadness whenever the topic is brought up. A couple of weeks before I am to leave Tanzania for Sweden (March 2022) I learn that the women's separation from PAC had been encouraged and supported by a young, female American who came to Tanzania as a volunteer.

I am told that PAC does not receive any governmental support, even though the organisation's work go hand in hand with the Plan of Action (2021-2031) adopted by the Executive Council of the African Union (AU) and the Convention on the Rights of Persons with Disabilities (CRPD), ratified by Tanzania in 2012. It is the civil society, rather than governmental-led actions that drive measures to protect and support PWA[10]. Tanzania is yet to develop a National Action Plan (NAP) on Albinism. It can be compared to Uganda's recent adoption of a NAP on albinism in 2022 (Kamurungi and Oketch, 2022) and Malawi which is to re-launch its NAP on albinism. One can certainly criticize the Tanzanian government for delaying with such an essential plan, not least since the highest numbers of harmful practices against PWA in sub-Saharan Africa (SSA) has been reported in the country. In addition to this, how come that the government does not support local organisations like PAC to fulfil their obligations and meet the goals of the CRPD and Plan of Action?

Our conversations about money stress Sr. Martha, not because the topic is sensitive (although it might as well be), but because it burdens her. She recently said to Edmund that she does not know how long PAC can survive and instead she considered becoming a saleswoman at the *"soko"* [market] to increase her earnings. But when I ask her how much she might make

---

[10] Especially two international organisations – Under the Same Sun (UTSS) and Standing Voice (SV) have been successful in their work to advocate for the albinism community in Tanzania, as well as Malawi.

it does not seem to be more than her current earnings. “And then I might be exposed to the sun”.

3.2.3 Health and Life

Working outside, as most people with albinism in SSA are forced to do due to lack of education, increases the risk of developing skin cancer due to the daily exposure to UV-rays. It is estimated that only 10% of people with albinism in Africa live for more than 30 years and 2% live past their 40th birthday (Smith, 2008; Forner and Ortiz, 2018; Rao, 2018). The arms, head and neck are especially exposed to the sun, and 80% of non-melanoma skin cancers are found on these body parts (Lund, 2001:5). Sr. Martha shows me a scar on her ankle from a surgery to remove skin cancer. For eight months, she visited the hospital every day to clean the wound to prevent infections. It costed her 1,716 USD[11] (from field diary, December13, 2021).

Some parents and relatives who are aware of the low life-expectancy for PWA – but not that skin cancer is caused by UV-rays, thus preventable – think it is a waste of time and money to invest in the child’s education and future. Insufficient knowledge about protective measurements and the importance of regulatory skin check-ups in combination with scarce numbers of dermatologists leads to painful suffering and social exclusion as the skin cancer, often located on visible body parts, develops. Sunburns and wounds are often thought to be an unavoidable part of the condition which keep some individuals from seeking medical treatment until it is too late.

Other health concerns for people with albinism are their visual impairment and the life threat of being attacked. One of the twin sisters with albinism often squints her right eye and moves her head instead of the eyes when focusing her sight. Her head tilts as she looks at me and tells how her siblings do not understand why she and her twin sister are not black. “You are not our blood-relatives”, they say and close their eyes for the sisters’ needs, as they have done for the past 18 years. From the age of three, she and her twin sister either stayed at the boarding school or at Sr. Martha’s place. It was unusually early, even in Tanzania, but necessary to protect their lives. The neighbourhood had gossiped how their older brother had been in contact with a thief to allow him to mutilate his sisters’ bodies in exchange for money (from field diary, February 18, 2022).

---

[11] Converted from TZS to USD, 30-10-2022.

The persecution and deadly violence against people with albinism might be the most shocking form of discrimination. The phenomenon of mutilating, kidnapping, or killing individuals with albinism for the purpose of accumulating wealth and success through rituals and traditional medicines rose in African countries in the late 2010s[12].

Since the 1970s, a total of 758 violent attacks against PWA have been reported in Africa; 96% of the attacks took place between 2006 and 2015. Malawi and Tanzania have the highest numbers of reported mutilations and killings of individuals with albinism (Standing Voice, 2021, see Figure B2 for an illustrative map). By 2015, 64 survivors and 76 killings had been reported in Tanzania alone (PAC, 2015), but it does not account for last year's (2021) four killings (Dghar, 2022). Even though the numbers sound small compared to the deaths in armed conflicts the viciousness of the crimes creates an atmosphere of terror for people with albinism living in SSA. In addition to this, one should keep in mind that reported attacks and killings against PWA are likely underestimated since many attacks go unreported, including the killings of children with albinism at birth (Standing Voice, 2015), so called "mercy killings" (Oestigaard, 2014:184). At the same time, some believe the seemingly rising presence of Tanzanians with albinism – in comparison to a few decades ago – is because of a decrease in infanticides. It is a positive progress which acknowledges babies with albinism their right to life.

Another point needs to be made. While mutilations and killings only have been reported in Africa it should not lead us to assume that deadly violence is non-existent elsewhere but could as well be unknown. Following section presents cases of crime against PWA in East Africa to demonstrate the atrocious acts of violence and why Sr. Martha works to protect children with albinism.

3.3 Physical Violence

"I do not understand why they trouble her so much. She has been around places, that girl" says Sr. Martha as she tells me about Small S who has moved from relative to relative because of fear that someone might hurt her.

Some children do not have the good fortune of Small S in evading the violence. Miriam Emmanuel, a five-year-old girl, was reported murdered in 2008 in Mwanza (Tanzania). Her

---

[12] It is believed that killings of new-born babies with albinism was commonly practised prior to the more recent phenomenon.

sister witnessed the horrific violence. While asleep, her legs were chopped off, and her throat was slit open from where her blood was poured into a cooking pot and drunk by the killers (Obulutsa, 2009; Ravi, 2009; Burke, 2010; York, 2010). Mariam's remains were buried inside the house for fear of grave robbers (Malone, 2009; Ravi, 2009). It is believed that body parts are more potent if hacked off when the victim screams, hence is alive (Oestigaard, 2014:186; Taylor, 2015; Wullfhorst, 2015; Steen, 2019a). The younger the victim, the greater the power.

Survivor Emmanuel Festo was five years old (2007) when he was attacked by two strangers at home (Tanzania) while playing with other children. The strangers asked for water to drink. As Emmanuel's sister went inside their house to get water, the strangers attacked Emmanuel. They chopped off his left arm and the fingers on his right hand and injured his jaw when they tried to pull out his tongue and teeth (Taylor, 2015; Steen, 2019; *The Hunted Children of Tanzania: Mutilated for Profit*, 2019).

Another boy, Baraka, was attacked and lost his hand in 2015 – his father was suspected of the crime (Wullfhorst, 2015; Steen, 2019). It is not uncommon for relatives or neighbours to a person with albinism to sell information to thieves or participate in the act of violence like in the case of Mariam Staford Bandaba (see *Tanzania Albino Attacks: 'My Neighbour Hacked Off My Hands'*, 2017; Wesangula, 2015). Stigma and lack of adequate laws for vulnerable and disabled people prevent convictions of perpetrators even when they are identified.

My mother and I are joining an online event hosted by UN Geneva in June 2022. The documentary *In the Shadow of the Sun* by Harry Freeland (2012) is screened followed by a panel discussion with the film director, Bonface Massah [13] and Muluka-Anne Miti-Drummond[14]. My mother and I sit in silence and cry together when the documentary shows how several people travel in a car on rough roads in a remote area while the narrator tells us about the rising deadly attacks in Tanzania. The camera zooms in on a stuffed blanket on a mattress on the car's floor. Next scene: people are grieving, a woman cries out loud. The car approaches the grieving mass. Several men help to carry what is covered in the blanket. With hands grabbing the object, the contour of a small body appears obvious. The woman screams.

Respondents have shared how they live in constant fear of being attacked or killed in the most horrendous way. And survivors bravely recall memories of incidents and how they cope with the trauma. In a reportage and documentary (*The Danger of Living With Albinism in*

---

[13] Country Director of Standing Voice in Malawi and Human Rights Commissioner in Malawi (UN Geneva, 2022).

[14] Independent Expert on the rights of persons with albinism (UN Geneva, 2022).

a Highly Superstitious Society, 2020), Nixon Lugadiru from Kenya tells the journalist Kaberia (2020) how he found his older brother Enock in a pool of blood in his bed; attacked and stabbed with machete; hospitalised for one week but succumbed to the injuries. Another Kenyan, Robinson Mukhwana describes to Kaberia (2020) how he was rescued from being trafficked at the Tanzanian border. A friend named Mutei had offered him a job in Tanzania and Robinson left Kenya in the belief that he would become employed. Instead, he fell in the hands of a human trafficker. Robinson was rescued by a police team who set up to trap the trafficker by going undercover as an interested buyer. Robinson told the reporter:

> It was not the first time he [Mutei] had trafficked people with albinism. I was the third. The first was the body of a [deceased] three-year-old-girl from Kibomet in Kitale. The second was a 23-year-old boy from Matise in Kitale – the boy had been cut into pieces. I was shown a bone of the 23-years old. It was still at the police station. (Kaberia, 2020)

Violent attacks have decreased significantly since the peak in 2008. Yet, killings and grave robberies were reported as recently as 2021 in Tanzania and 2022 in Mozambique and Malawi. Worrisome is the rising number of attacks reported from Madagascar since 2020 (Obaji, Jr., 2022). The latest kidnapping of a child with albinism in August 2022 led to a lynch mob where 18 people died as the police opened fire against the protestors (Obaji, Jr., 2022).

In May 2021, a six-year-old boy was mutilated and murdered in western Tanzania. In the report one could read: "according to witnesses of the incident, the body was found with severed arms, his eyes removed, and his left ear and genitals hacked off' (LHRC, 2021).

Relatives who have lost their child, sibling, aunt, or parents struggle to get justice. The same goes for survivors. Low levels of literacy and human rights awareness in combination with the social stigma which accompanies albinism discourages many to fight for justice. For those who find the courage to seek justice are few executors charged for the crime. At the same time, the ones who get caught of murdering a person with albinism face death penalty in Tanzania (BBC, 2015; Makoye, 2015; Ongiri, 2015) and Malawi (Masina, 2019).

During a conversation with Sr. Martha in March 2022, it becomes apparent how difficult it is to hold perpetrators accountable for their actions against people with albinism. Sr. Martha tells me how the elderly people in the Maasai village refused to take legal action against the father who had tried to kill his son with albinism. They told Sr. Martha that they respected her work but gave the boy to her and said: "There is no place for this child here, he does not fit. He is your son, you look alike" (from field diary, March 16, 2022).

3.3.1 Boarding Schools and School Breaks

Boarding schools with their higher security have come to be a comparatively safe place for children with albinism who are the main target for harmful practices and murders. Although boarding schools are common in Tanzania, they are expensive and not every family can afford it. During school holidays CWAs need to leave the campus (like all students). Some of them travel to their home villages and families, while others cannot, due to safety reasons. It might be that parents or guardians cannot afford sun-protective means (e.g., sun hat, sun lotion, thick clothes), or they might neglect the child's mental and physical needs because of stigma, ignorance, and lack of awareness. Or the child's life could be in danger. Perhaps people have tried or succeeded in harming the child, or there are ongoing rumours about intending to harm him or her.

The day we visit the school, I notice that many of the children's school uniforms and shoes are worn out. Some children's faces are dirty with runny noses. A smell reaches my nostrils and reminds me about the time I volunteered at an orphanage in central Tanzania. It takes a moment before I realise what the smell is. Then I also understand why my brain links it to a specific memory. It is the smell of urine dried into clothes. Sr. Martha ensures me the children "are doing great here". She tells me that some of the children who travel home during school holidays return with severe sunburns and their needs completely neglected.

Sr. Martha opens her home for children who cannot return home during the school breaks because of "people without a good heart". As of summer 2022, she knew of 19 children who would not be able to return to their home villages. But when I call her a day in May (2022) she sounds stressed and doubted if she would be able to host all children in need of a shelter during the break because of rising food prices due to climate changes, gas scarcity, the Ukraine-Russia war, and the Covid-19 pandemic. Despite the financial challenges Sr. Martha and her husband face, she is determined to help these vulnerable children:

> It is not a must to have these children, but come to God's love, it's very, very difficult for us to decide that. We're falling in tears when we feel that this [economic situation] can be a reason for us, really, not to stay with the children […] Sometimes I say: "I better die before these children are to leave". Because I feel that "who will stay with them?"

Silence. I try not to fill seconds of silence with my affirmations or more questions. I wait for Sr. Martha to continue, and when she does her voice is shaking and tears fill her eyes:

> This situation is very hard. But I don't want to really leave the children, I have never seen anyone who have offer to stay with these children who have that kind of special need. And if me, I will also feel that I can't, I feel that it's like now I am throwing them to the fire, which I don't want [to] happen. (Interview with Sr. Martha, January 7, 2022)

3.4 Psychological Violence

"Why do you want to go there? No one wants us there. No one loves us". The boy, who had been kept in a fenced area in the family's home until Sr. Martha became his guardian when he was five years old, asked the boy who nearly was killed by his father. The first boy had been hidden from neighbours; living and sleeping in his excreta; never allowed to play with his siblings. He could not understand why his friend kept dreaming of going back to his so-called "home" when the villagers kept showing him inhospitality whenever Sr. Martha took him for visits (From field diary, March 16, 2022).

Children and women with albinism are particularly vulnerable to stigma, marginalisation, psychological and physical violence. CWA face major obstacles already in their childhood. Some children are abandoned by one or both parents. And several adults testify to have been raised by their grandparents. Daily life for many includes being called derogatory names and being a victim of ostracism.

A study conducted by Aborisade (2021) in Nigeria shows how the emotional well-being of CWA is damaged by prejudice and violence in the family settings. Consequently, this leads to low self-esteem and self-worth. Contrary to other studies, Aborisade (2021) suggests that discrimination and maltreatment perpetrated by family members are much higher than previously thought. Family-based violence, as opposed to community-based violence, takes all forms of abuse – emotional, economic, physical, spiritual, social, and verbal – and has long-lasting impacts on the emotional development of traumatised children. Respondents of the study had in their childhood experienced their family's denial for educational and vocational training, denial to participate in social activities, physical violence performed by family members but encouraged by religious and spiritual leaders to chase out evil spirits, being called "demeaning names", they were thought of not being able to fulfil intellectual and physical tasks.

The adults in the study by Aborisade (2021) adopted various coping strategies as children to deal with negative behaviour towards them, such as consumption of alcohol and other substances, religious and spiritual coping, and withdrawal from others. Alcoholism amongst people with albinism has also been reported in Mali (Ero, Muscati and Annamanthadoo, 2021:85). Indeed the Adverse Childhood Experiences Study (Fallot and Blanch, 2013:372) shows that trauma in childhood risks leading to mental health problems, substance usage, impaired work performance, physical health problems and mortality.

Sr. Martha was 19 years old when she threw herself into the river that floats through the flat landscape where families farm the land; a few houses appear as sugar cubes dropped on the floor; mountains in the far distance. We visit her village one day in January 2022. It is the dry season and the white sand blows into the *bajaji*, [autorickshaw], where we are seated. As we cross a small bridge, she points to a place that seems to be beyond what we can see: "Over there is where I tried to kill myself". The river has dried up and its wide channel meanders like a snake. I imagine how brown water quickly runs down the river during the rainy season, almost hidden by high grass on the surrounding land area. The bajajidriver tells us there once was a crocodile living in the river.

In his study, Aborisade (2021:1989) shows that some respondents had experienced so-called "spiritual-induced physical violence" in mainly churches to chase out evil spirits. He writes that three participants "reported that parts of their bodies like ears, toes and palms were burnt with fire and their hairs shaved in a bid to stop their parents from further bringing forth albino children" (Aborisade, 2021:1989). Aborisade (2021:1091:1089) concludes that religious organisations influence the social perceptions about albinism and impacts of prejudice might last much longer than the trauma of physical violence. One of the respondents told Aborisade (2021:1090):

> …you know that's what my family wanted, for me to remain unseen and unheard. So when I kept to myself, they were not bothered at all. But it does not feel nice when you have to be in the bedroom when you wished to be in the living room and laugh with everyone, talk with everyone and be part of their lives. But, then, when I was in their midst, I would be the subject of their laughter and the one to vent their frustrations on when they were not happy.

A life-long experience of being neglected and a feeling of being a burden to her mother, led Sr. Martha to the decision to end her life. While in the cold water she describes how she heard a voice and somehow managed to pull herself up from the river:

> I heard a voice from God, "Do not be afraid, I love you". And when I get that message, it was like someone came and took out of me a very heavy burden […] Knowing that in my heart, now I am here by God's purpose, no matter no one loves me, God loves me. So, I promised God that if you will help me not to die soon or disappear like other people say I will help my fellow with albinism, and families of people with albinism. (interview with Sr. Martha, January 7, 2022)

3.5 Religious and Spiritual Coping

The attempted suicide left Sr. Martha with a feeling that God had revealed his love and message to her: "God loves me and I am here by his purpose, not by accident and I can do everything through him who gives me strength" (interview with Sr.Martha, May 2022).

Sr. Martha´s faith is a recurring theme in many, or, in all our conversations and phone calls. It fascinates me how she puts her trust in God during times of hardship and praises God for all good outcomes. More than nine-in-ten surveyed in Tanzania find religion to be "very important" in their lives (PEW, 2010c:3). In 2010, 60% of the Tanzanians identified with Christianity, 36% with Islam, 2% with African Traditional Religions and only 1% as atheist or agnostic (PEW, 2010c:20).

Coping with the trauma and discrimination in a religious and spiritual way became essential for Sr. Martha but has also been important for other respondents with albinism in numerous studies and reports. Similarly to Sr. Martha, a Ugandan respondent with albinism copes with prejudice by reminding himself that God is the creator, therefore, he is "part of the society like any other person with or without a disability" (Mugeere *et al.*, 2020:72).

Gall and Guirguis-Younger (2013:353) review several studies which have shown the positive outcome religious and spiritual coping had on some individuals' psychological and physical well-being in treatment. Strategies, according to Siegel, Anderman and Schrimshaw (2001:632, cited in Gall and Guirguis-Younger, 2013:354) allow people to interpret events, improve coping efforts and increase access to social support. At the same time, negative religious coping might worsen levels of anxiety and depression (McConell., et al., 2006 cited in Gall and Guirguis-Younger, 2013:355). Literature on the effects of religious and spiritual coping for life stress is to a large extent limited to cases in the US and a handful in the UK and South Africa. These studies have focused on the positive role of religion and spirituality for individuals to cope with stress caused by victimization (e.g., childhood trauma, domestic violence, gender-based violence, terrorist attacks), chronic illness (e.g., cancer, HIV/AIDS), end-stage pulmonary disease and depression.

The mental well-being of people with albinism is an often-forgotten topic. With the exception of Aborisade's work (2021), the psychological wealth is seldom mentioned in newspapers, reports, studies, or the preliminary focus-area for organisations working with persons with albinism. Indeed, Ero, Muscati and Annamanthadoo (2021:85) address the lack of psychosocial support for this vulnerable group. Regarding religious and spiritual coping, there is a need to understand these dimensions in its local context to provide appropriate and effective assistance to trauma survivors with albinism. This will also lead to better understanding of what Tedeshi and Calhoun (1996, cited in Fallot and Blanch, 2013:372) refer to as posttraumatic growth. Sr. Martha smiles when she hears the occupation of my father – a child and adolescent psychiatrist – and suggests that he comes to support the children with albinism in Tanzania.

Furthermore, a step in improving the psychological support is to ask: how does trauma impact the religious and spiritual beliefs of a person with albinism and how does religious and spiritual coping affect the mental wealth of person with albinism? Fallot and Blanch (2013:379) remind the reader that "any consideration of the role of religion and spirituality in trauma healing must begin with the recognition that some religious leaders are perpetrators, and some religious structures may be seen as enabling abuse".

In an e-mail correspondence, I asked the former UN Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, to what extent religious and traditional leaders uphold prejudice against PWA. In a voice-note, sent to me on Whatsapp (February 8, 2022) she said that there is a lack of comprehensive studies on the topic. Certainly, there is a need for scholars and human rights advocates to analyse the influence and role of religious institutions and leaders in combating as well as contributing to discrimination and abuse against PWA, at the community and family level. The following chapter pays greater attention to several factors causing negative attitudes and harmful behaviour against PWA.

Chapter 4. Instrumentalising Rumours

Sr. Martha is telling me about the time she met with traditional healers to debunk harmful myths about people with albinism. Naturally I must ask if she was afraid; after all she agreed to meet with strangers. Her answer surprises me, because she did not seem to fear being attacked, but to meet with what she called “a witch”. “Maybe he will turn into a big snake”, she said with a big laugh. I ask her if she believes in witchcraft, and she replies:

> By that time, yes! I have heard that […] there is witch-people who can even take you from your bed and you find yourself outside. Or who can make you become crazy, or […] can put a poison in your food or whatever. In my childhood I believed that, yes, there [are witches]. And I heard that also when you go to somebody – who people say he or she is [a] witch – they have a room which is locked all the time, when you get in you can find a snake, a big snake! Or in the roof there is people who are staying there; you may think that your fellow has died, but that witch has taken [them], so they are staying on the roof and during the night they are going to the farm. So, you can see [he] has a big farm, but few people who are digging […] or he is not that rich but how come for him or her to have lot of harvest? Many says, “from people [taken by witches]”. So, for me I was just afraid that there is maybe [witches]. (Interview with Sr. Martha, May 11, 2021)

This chapter argues for the invention of a new term – instrumentalising rumours – to describe what is causing discriminatory and violent behaviour against people with albinism. The purpose is to avoid simplified explanations and understand the driving forces for discrimination and violence from a more holistic point of view, to support PWA, prevent violence and strive towards social change. The chapter outlines what factors contribute to the persistence of stigma and harmful practices.

A significant large amount of academic literature and other media sources contends that abductions, violence, and mutilations are caused by superstition and witchcraft beliefs. Although true to a degree, such claims tend to simplify a rather complex multi sectoral reality and thereby reduces the chances to effectively change behaviours and attitudes, and ultimately end human rights violations. A sole focus on witchcraft beliefs and practitioners undermines the roles and responsibilities of traditional religious beliefs (i.e., Christianity and Islam), traditional African religions, and religious leaders in justifying stigma and motivating abuse and violence. So, I have chosen to coin and use the term “instrumentalising rumours” when talking about the belief that the body or parts of the body from a person with albinism can be used as an instrument to cause wealth and success, cure HIV/AIDS and break bad omens. More generally, I suggest that we conceive of instrumentalising rumours as stories that ascribe to people a utility that can be appropriated by ignoring their human dignity[15].

Here, I would like to make two clarifications about “instrumentalising rumours”. First, regarding the definition of rumour as “an unofficial interesting story or piece of news that might be true or invented, and quickly spreads from person to person” (Cambridge Dictionary, 2022b). No instrumentalising rumour about albinism is true. I choose to use “rumour” over “myth” because of the easily spreading character of rumours that partly explain the sudden rise in attacks and killings of PWA in SSA since 2006. Second, it is a conscious decision not to further define belief (e.g., as superstitious, religious, or witchcraft) when using instrumentalising rumours. I argue that we cannot assume the spread of “instrumentalising rumours” to be tied to a specific group of believers. As will be shown, a person who believes in instrumentalising rumours can still affiliate with one of the major religious traditions.

4.1 The Coexistence of Various Beliefs in Tanzania

The term “witchcraft belief” might give an impression of a group solely consisting of witches or witchcraft believers; such is not the case in Sub-Sharan Africa (SSA). Professor Ransford-Oppong (2010:159) and the report Tolerance and Tension (PEW, 2010c:3) show that many who identify with one of the two major religious traditions in SSA – Christianity and Islam – still believe and practice African Traditional Religions (ATR). In the report it is written that: “large numbers of Africans actively participate in Christianity or Islam yet also believe in witchcraft, evil spirits, sacrifices to ancestors, traditional religious healers, recantation and other elements of traditional African religions” (PEW, 2010c:1).

In Tanzania, six in ten people believes in the traditional religious practice of sacrificing to spirits and ancestors for protection (i.e. protective power of juju) (PEW, 2010c:4). And it is

---

[15] For example, Oestigaard (2014) writes that bald people in Tanzania were targeted in the 1980s and 1990s for the same reasons people with albinism are being targeted in the 2000s. As such "there were rumours that bald people would bring prosperity and as a consequence, such people were reported decapitated, and their heads used in magic potions” (Oestigaard, 2014:184). In 2017, Mozambique reported its first killing of a bald person, the most recent incident took place in 2022 (BBC, 2017; Baloyi, 2022).

estimated that 93 per cent of the population in Tanzania, specifically, believe in witchcraft (Oestigaard, 2014:177). Meanwhile, one should remember that only 2% identify with ATR and 96% identify with Christianity and Islam (PEW, 2010c:20). With regards to the coexistence of various beliefs in the life of many individuals in Tanzania, a justified question to ask is if it then is needed to distinguish between types of beliefs? And if the answer is "yes", how to avoid the risk of giving simplified explanations that fail to take the many interrelationships between strands of beliefs into account? Before I further elaborate on the reasons to invent and use "instrumentalising rumours" as a term instead of witchcraft beliefs, I describe ATR and Africa's encounter with Christianity and Islam in the next paragraphs.

Africa is a mosaic of thousands ethnic groups (Felix, 2001 cited in Fisher, 2015; Gardiner et al., 2021) with rich linguistic and religious variations, thus, to describe every traditional religion is an ambitious task. Therefore, I give an overview on what the author Ambrose Moyo (2007) identifies as five phenomena common to most of the ATRs: (1) a belief in supreme being; (2) a belief in spirits; (3) a belief in life after death; (4) religious personnel and sacred places and (5) witchcraft and magic practices. Moyo (2007) writes that ATR, contrary to the Christian and Islam traditions, has no sacred scriptures on which faith and practice build on. Further, oral traditions, myths, rituals, and symbols have been the main ways to express the belief and pass it on to the next generation. Nature and humans are seen to live in symbiosis with each other. A dead relative becomes a mediator and a "guardian spirit" for the community, and God is worshipped through these ancestor spirits (Moyo, 2007:321-2). Blessings and curses are given by ancestral spirits on behalf of God – who is the creator – for an individual's success or mistakes (Moyo, 2007). In many aspects, African Christians and Muslims have sought ways to incorporate traditional beliefs and practices into the Abrahamic religions that will represent the African identity, manifested in spiritist churches (Ransford-Oppong, 2010). These churches are by Ransford-Oppong (2010:159) explained to combine "elements of traditional ancestral worship with elements of Christianity and Islam".

Traditional healers have a central role in ATRs for treating various health-related problems, and identifying the cause of one's misfortune, to end it through medicine or rituals. African traditionalists protect themselves, their families and property through magic from enemies, witches (females) and sorcerers (males) who are believed to cause harm and hardship. Magic is also used to curse and destroy lives to accumulate wealth.

Although Christianity in Egypt dates to the first century, it was not till the 1900s that Christian traditions began expanding significantly across the African continent. The Scramble for Africa in 1884 led to increased Christianisation, used as a strategic colonial tool for

Europeans (1884-1960s) to manage the indigenous people. The Christian belief came to challenge ATRs and change traditional structures (e.g. kinships) in African communities (Gordon and Gordon, 2007; Yeboah, 2010:114). The bringing of European Victorian values into some African matrilineal societies enforced patriarchal structures and reduced the political enjoyment (Schraeder, 2004) of women which, according to Turshen (1987 cited in Gordon 2007), led to higher fertility. Gordon (2007:209) states: "European Christianity and missionary education also inadvertently encouraged larger families. Missionaries, as well as other colonial agents promoted Western Victorian ideas of women's 'proper role' as dependent wives and mothers rather than encouraging women's productive activities outside the family".

The early spread of Islam in SSA is, to a large extent, considered less aggressive than the quest of Christians. Islam began expanding through the trans-Saharan trade and Indian ocean trade routes from Arabia (Moyo, 2007; Yeboah, 2010:102). By the late 600s, Persian and Arab traders had brought Islam to the east and south coast of Africa. Islam became a religious tradition associated with the elites and rulers during the latter part of the Middle Ages because of its cosmopolitanism and similarities with African cultures, traditions, and practices. New forms of architecture, education, language, and law came with Islamisation in many African states, and Muslims were often hired as colonial administrators because of their literacy by the Europeans (Yeboah, 2010:105). The professor of Geography, Yeboah (2010:105), states: "Islam and indigenous cultures were more of a conversation than a conversion or domination".

Moreover, in SSA, many people with different socioeconomic and religious backgrounds believe in witchcraft and magic (Moyo, 2007:326). Spiritist and mission churches that emphasise the Holy Spirit often practice chasing away evil spirits, identifying witches, and blaming sorcery for misfortunes (Moyo:333-4). The belief in witchcraft and the use of charms is also prevalent amongst Muslims (Moyo:342). Moyo (2007:326) writes that superstition "represent[s] ways in which people try to explain the causes of misfortune or social disorders. Misfortune, sickness, or death may also be explained as an expression of one's ancestors' displeasure regarding the behaviour of their descendants".

4.1.1 Beliefs and the Persecution of People with Albinism

Much of current literature, articles, and reportage on the persecution of people with albinism, but also state-led incentives to end the violence focus on superstitious beliefs, witchcraft, and sorcery. My concern is that such trend undermines and neglects the roles played and to be played by religious leaders and institutions in motivating and combating harmful practices and violence against PWA. As shown in the study by Aborisade (2021), adults with albinism experienced so-called "spiritual-induced physical violence" in churches during their childhood. The PhD researcher Francis Benyah (2017:165;180) goes further, and claims that religious and cultural beliefs cause discrimination against Ghanaians with albinism. The author raises a concern that has not been given much thought in previous studies, namely, the influential role of religion and culture in legitimising stigma and discrimination against people with albinism. This position is further developed into an argument that "most legal instruments that seek to deal with human rights issues tend to neglect the role played by religion in the implementation and translation of such rights in various cultures" (Benyah, 2017:165). This tendency is doomed to create ineffective measurements to challenge the stigma if there is no inculturation of human rights (Benyah, 2017). More to the point, a Catholic priest in Malawi was in July 2022 sentenced for the killing of one man with albinism named MacDonald Masambuka (aged 22) (Masina, 2022; Nzwili, 2022; The Citizen, 2022). The case is a clear example how religious leaders also believe in and spread instrumentalising rumours.

In addition to this, the difference between a traditional healer and a witchdoctor are seldom understood and the terms are used interchangeably when explaining who is behind the harmful attacks against PWA. It is during the reconciliation-meeting with traditional healers[16] that Sr. Martha learns that they are not all using human organs in their practice. The Docent at the Department of Archaeology and Ancient History at Uppsala University, Terje Oestigaard (2014:160), furthermore, distinguishes between two trends in witchcraft, where the most recent trend includes the usage of human body parts in medicines and killings of people, including persons with albinism. Traditional healers would in the past obtain their role, powers, and influence from their ancestors with an important mission to maintain social relations within their community. Traditional healers only use herbs and plants in their medicines (Oestigaard, 2014:190). Today, the preliminary focus has shifted to accumulate wealth for those who believe in witchcraft by using organs. It has also become easier for anyone to proclaim themselves as traditional healers (Oestigaard, 2014:162).

Another reason to avoid using "witchcraft belief" is that a colonial understanding of witchcraft per se, remains widespread. That is, consciously or unconsciously, classifying beliefs in witchcraft or magic as (less) irrational and primitive in comparison to the traditional

---

[16] Defined by Oestigaard (2014:160) as someone "who engage in witchcraft by providing and securing the medicines used in witchcraft, but also the counter-medicines to protect people from it".

religions. The European enforcement of a "religion/magic dichotomy" during the period of enlightenment and rationalism followed the persecution of witches in Europe between the 1300s and 1600s (Wallace, 2015:30). In a paper on witchcraft discourses in South Africa, the Dr of Philosophy Dale Wallace (2015:30) argues the socially constructed division of – religion, and magic – to be a colonial strategy for effective colonial rule. The author (2016:36) further stresses the need to decolonise western-produced definitions of the phenomenon (i.e., witchcraft) and realise its marginalising effects on traditional African religious expression. It is therefore quite notable to find that in an article on factors associated with negative attitudes against PWA, the authors, Masanja, Imori and Kaudunde (2020:528) write: "The killings indicate that there are some primitive, superstitious beliefs attached to the people in the study area that make some wicked men continue hunting PWA". Describing beliefs as "primitive" is problematic, not least because of its historical use amongst explorers and writers during the colonial era which might get associated with eurocentrism.

There are reasons to use the word "witchcraft" with great caution and keep in mind that witch accusations kill innocent people too, mostly elderly women and children. Between 1970 and 1984, 3,693 men and women in Tanzania were accused of witchcraft and were consequently killed. An average of 517 alleged witches were killed per year under a period of five years (2004-09) (Oestigaard, 2014:180-1).

Moreover, "instrumentalising rumours", a term free from spiritual-religious-distinctions, allows the thesis to take a stand against power structures reinforced through the usage of words. Nonetheless, problematising the conceptualisation of witchcraft in the African context might get perceived as an irrational effort to defend those who believe, spread, and commit crimes because of instrumentalising rumours. Therefore, I found it necessary to clarify that it is not what I do. I want to shed light on the many interlinking parameters to better understand these harmful beliefs: what causes them to spread and amongst who? My hope is that a more nuanced understanding will result in a more holistic approach to support and protect people with albinism in SSA and elsewhere that will include more stakeholders.

Another important question to ask is why instrumentalising rumours spread? In the next sections I lay out some of the contributing factors for maintaining and spreading instrumentalising rumours.

4.2 Factors Contributing to Violence and Killings

4.2.1 African Ethical Worldviews

I received an e-mail (27-06-2021) from a person who bought tote bags from me to support Sr. Martha’s work in Tanzania and raise albinism awareness in Sweden. The person wrote: “I welcome your engagement for these vulnerable people with albinism. I met them in Somalia as a banned group that was placed on an island in the Juba River together with lepers. Totally separated from other people”.

One could wonder why groups of people get shunned from the society. And even displaced like one of my Facebook followers said about people with albinism and lepers in Somalia. The lecturer in the Department of Religions and Philosophies, Imafidon (2017:163;168) argues that stigma, discrimination, and violence against PWA in African countries partly is explained by the practice of “othering”. Community members perceive (fear) and treat a person with albinism different from the status quo because of their physical appearance and “ontological other”. Mistreatments and violence against a group are justified by perceiving them as the “other”. Further, Imafidon (2017:163) claims that there must be a shift from the African ethical (norms specific to a group) point of view to a moral (universal norms and common humanity) point of view to change negative attitudes against PWA. According to Imafidon (2017) several groups of human beings are socially excluded and isolated, despite the often proudly referral to African ontology as being “all-inclusive” and “solidaristic”. Why ostracism occurs is explained by Imafidon (2017:166):

> The basic reason… is to protect the socially approved web of relationships from anything that may threaten its harmony and equilibrium, for instance some have wondered what justification may be given for the stigmatization against victims of deadly, contagious, and (previously) incurable in African traditions.

Such individuals who do not fit the status quo, varying from twins, triplets, people with albinism or leprosy, contagiously ill or evil people are excluded to protect the harmony of a community (Imafidon, 2017:166;169). Because of the ontologically difference associated with albinism, acts of violence are convinced as necessary, thus “morally permissible”, to sustain the equilibrium (Imafidon, 2017:169). The leap from the ethical point of view to the moral point of view is subsequently essential for attitudinal and behavioural change towards people with albinism as well as other vulnerable groups in Africa (Imafidon, 2017:169;172). Disability theology can also reveal how attitudes and behaviour towards disabled people, including PWA, is formed and internalised, such as perceiving disability as a punishment (Otieno, 2009 cited in Mugeere *et al.*, 2020:65)

4.2.2 Socio-economic Factors

Masanja, Imori, and Kaudunde (2020) collected data from 156 respondents living with a person with albinism in remote areas of northern Tanzania where several attacks and killings of PWA have occurred. The study sought to explore negative attitudes about albinism and towards PWA amongst PWAs themselves and their relatives. More than 80% of the researched proved to have negative attitudes which the authors linked to factors of educational level and occupation. Similarly, level of albinism awareness among respondents were associated with age, social status, sex, occupation, religious affiliation, educational level, and ethnic groups. Remarkable, only 12% of the respondents with albinism proved to be highly aware of albinism. The authors concluded that lack of awareness and negative attitudes pave the way for stigmatisation and victimisation of PWA and argued for the importance of education to challenge negative attitudes about albinism within communities.

The sudden rise in killings and trade with body parts in the mid-2000s is partly explained by the boom in the mining and fishing industry (Engstrand-Neacsu, 2009; Wesangula, 2015) and an uneven economic development. It is also evident that attacks and killings in Malawi and Tanzania increase during times of elections as politicians seek "electoral fortune" (UN, 2013:7; Mis, 2015; OHCHR, 2019; Ero, Muscati and Annamanthadoo, 2021:34).

Regions near Lake Victoria[17] (northwest Tanzania), where numbers of fishermen and miners reside and operate, have been especially troubled with killings of PWA but also witchcraft accusations and killings of allied witches (Oestigaard, 2014). It is believed that hair from a person with albinism, weaved into a fishnet will grant a great catch. Meanwhile, miners are told to wear charms or spread the powder of crushed bones of PWAs inside mines to find desired metals or gemstones (Malone, 2009; Ravi, 2009; Mbogoni, 2013:117; Schüle, 2013; Hairapetian, 2014; Oestigaard, 2014; Taylor, 2015; RFI, 2016). Ero (cited in RFI, 2016) raised that the deadly violence ground on people's jealousy of individuals' emerging wealth. It is not

---

[17] [17] E.g., Mara, Mwanza, Shinyanga and Sukuma (Mbogoni, 2013; Schüle, 2013).

unusual for people to be suspicious about someone's success and explain or curse widening wealth gaps with reference to divinity and magic (Oestigaard, 2014:172).

Judith Schüle (2013:15) suggests that the rise in violence and killings against PWA are caused by the commodification of human body parts to use in wealth-brining-potions. According to Schüle (2013:13;18) traditional doctors saw the potential for a profitable but inhumane business – ranging from 2,000 to 75,000 USD for a limb or whole body respectively (Wesangula, 2015) – when the mining industry, already a dangerous workplace as it is, hit several obstacles in northwest Tanzania in 2006. Schüle (2013) thus argues that entrepreneurial forces motivated abduction and killings because of the sudden rise of killings in the early 21st century. It suggests that targeting PWA is a relatively new phenomenon and not part of traditional practices but fed by rumours and economic deprivation (Schüle, 2013:5; see Oestigaard, 2014:191). A respondent informed Schüle (2013:22) that "Witchdoctors do not really believe in this magic, selling the bones is just a business for them. In a way they do get rich".

Certainly, the great profit made from human trafficking and selling of body parts on the black market led to an expansion of the barbaric business across borders of African countries. Harmful practices against PWA and incidents of killings are being reported in Burundi, DRC, Mozambique, and Ivory Coast to mention a few (see Figure B2).

On a similar line, the write Ahmed Khan (2013) writes that attacks and killings are not just a consequence of witchcraft beliefs but links to local understandings of globalisation and modernisation:

> Far from being purely an enigmatic throwback to irrationality and tribalism, the attacks can be seen as part of a modern disquiet at growing inequalities related to production, consumption and accumulation…Protecting PWA requires an acknowledgement of the dynamic role witchcraft plays in addressing popular understandings of capitalism and morality. (Khan, 2013)

The potential relationship between witchcraft, attacks, and crisis – be it a personal or social crisis – is somehow supported by a recent statement made by Ikponwosa Ero, the former Independent Expert on the enjoyment of human rights by persons with albinism. She announced in June 2021 that killings of PWA increased in the shadow of the Covid-19 pandemic because of increasing poverty (OHCHR, 2021; Román, 2021a).

At the same time, blaming stigma and harmful practices against PWA on witchcraft beliefs, as often been the case in popular media coverages, is a dangerous simplification of the phenomenon. As shown, socio-economic factors play their part and beliefs in “instrumentalising rumours” are not tied to a specific group of believers.

Chapter 5. Engaging the Public

5.1 Fundraising Appeals and Humanitarian Photography

> I follow you [on social media]. Therefore, I know that the money [I donate] will reach the recipient without disappearing along the way. A reliable actor is very important to me. In addition, I can follow what happens with the project I have chosen to support. (Translation from a donor's message, 8 April 2022)

I never anticipated that my first post about Sr. Martha and her organisation would touch so many people who, in addition, wanted to help by donating money. The recurring engagement and generosity shown by the public since then never stops to amaze me. Why do they show compassion with Sr. Martha and why do they donate money?

In this chapter, I discuss donor giving from several theoretical perspectives and reflect on the public's responses to stories I told about Sr. Martha and albinism. I identify and categorise four types of responses: (A) social media interactions; (B) donor giving; (C) buying one Albinism Awareness product and finally (D) participating in a public lecture, a webinar or an art exhibition. I will come back to the categorisations and explain them in more detail later in the chapter. However, because I collect, analyse, and present data on public responses from my social media followers, I found it important to clarify that I do not have a hidden agenda to experiment on or manipulate people's altruism. It was not until I formulated the research question that I realised it would require me to pedagogically present what responses the stories had led to. It gave birth to a curiosity to understand why generosity towards victims emerges. Thus, I turned to studies on donor behaviour and humanitarian photography.

To begin, one can ask: who is a victim? Everyone who suffers? Is a negative perception tied to "victim" that partly shames the victim for their suffering? In her book *The Cult of True Victimhood*, Alyson Cole assigns four categories to a sufferer's personal qualities that make an individual a "true" victim. These are property, responsibility, individuality, and innocence. She further elaborates on this:

> […] The True Victim is a noble victim. He endures his suffering with dignity, refraining from complaining or other public displays of weakness […] The True Victim commands his fate; he does not exploit his injury to excuse his failures […] Victimhood

> is an individual status even if a group is injured collectively […] True victims have not contributed to their injury in any way. (Cole., M, 2007:5)

According to this logic, Sr. Martha would be considered a True Victim. However, I find it difficult to talk about her as a victim simply because she has never described herself as such. Regardless, why do some victims gain recognition for their suffering while others do not?

Several studies have shown that people´s willingness to donate time and money is significantly higher when the victim is identifiable compared to merely statistical victims: this is called the “identifiable victim effect” (Small and Loewenstein, 2003; Small, Loewenstein and Slovic, 2007; Slovic, 2010; Ein-Gar and Levontin, 2013). Moreover, factors such as the size of the reference group, information (e.g., name, age, gender, etc.,) and pictures of the identifiable victim trigger emotions of empathy and sympathy amongst people. Small and Loewenstein (2003:5) show that even a weak identification which is not personalised leads to increased caring. Meanwhile, statistical victims (e.g., car accidents, mass-murder, genocide) do not receive the same amount of attention and donations. People tend to value saving a life to avoid a loss over saving a life for a gain (Kahneman and Tversky, 1979 cited in Small and Loewenstein, 2003:6). It means that people prefer to help a certain victim (identifiable) over a probabilistic victim (statistical) (Small and Loewenstein, 2003:6). The two authors (2003) conducted experiments where participants had been given an opportunity to donate to determined beneficiaries (identifiable victims) and indeterminate beneficiaries (statistical victims). The results showed that the altruistic behaviour to donate more was higher when the victims were determined (i.e., specified) contrary to indeterminate victims.

In a later study, Small and Loewenstein with Slovic (2007) aimed to test the outcome of deliberative thought, thus making participants aware of the discrepancy in charitable giving to identifiable and statistical victims. The authors argue that charity efficiency could increase if people were aware of the inconsistency in caring and giving. However, their findings showed that while the donations to identifiable victims decreased when participants were made aware of the identifiable victim effect – donations to statistical victims did not rise. They concluded that “when thinking deliberatively, people discount sympathy towards identifiable victims but fail to generate sympathy toward statistical victims” (Small, Loewenstein and Slovic, 2007:143). In some cases, affections (emotional distress) triggered by identifiability rather than deliberative thinking result in more donations.

5.2 Humanitarian Photos

An image is said to be worth a thousand words. Think about the monochrome picture of a naked Vietnamese girl (Kim Phuc) who runs with other dressed children towards the cameraman, away from the thick smoke caused by a napalm attack during the Vietnam war 1972 (Figure B3). Or the photo of a starving Sudanese boy who has fallen to the ground, observed by a hooded vulture (Figure B4). Or the image of the Syrian refugee Alan Kurdi's small body washed ashore on a beach in Turkey (Figure B5).

Humanitarian photography since the late 1800s (Fehrenbach and Rodogno, 2015:6), has been a powerful, communicative tool for journalists, activists, international organisations and NGOs to convey their messages to politicians and civilians about ongoing conflicts, crisis and living situations to raise awareness of and contributions to humanitarian situations. Photos from African settings have often portrayed suffering children (at times together with their mothers) as the victims of crises and catastrophes, a rhetoric that according to the former BBC journalist and now Dr in Media and Communication, Kate Wright (2018:8) argues to draw upon Christian values.

I have always found photos, especially portraits of ordinary people, fascinating for the message communicated and artistic techniques used by the photographer. The capture of a moment: facial expressions, emotions expressed (or not expressed) and the surroundings – even if just blurred in the background – invite the observer to the destiny of a fellow human and open doors for reflections and emotions. I remember how the exhibition by the photographer Jonathan Torgovnik called "Intended Consequences" at Fotografiska touched me deeply at age 16 (2011). It was the first time I heard about the genocide in Rwanda in 1994. The portraits of women (and their unwanted children) with texts describing the experienced sexual violence projected horror on me when I was standing in front of the frames. I have found inspiration for my photos to raise albinism awareness in Torgovnik's work, but equally important in my stepfather's obsession for monochrome editing. He has encouraged me to explore photography, showed me the beauty of documenting the ordinary in life and taught me the art of using a camera.

Art and aesthetic knowledge are valued attributes to convey the message of a reportage. A picture editor interviewed by Wright (2018c:102) stressed that their readers on The Independent on Sunday preferred "beautiful" photos over "clichéd" photos. But what are a photographer's moral responsibilities? Who decides what is "beauty", and what about the voice of the photographed? The independent documentary photographer Mohammed Elshamy writes:

> As photojournalists, we are always making choices. We have to choose whether to label an event a "conflict" or "war", whether to label a group of people "protestors" or "rioters". We have to decide which photos to take, who and what is included in the frame, and who never appears. (Elshamy, 2019:59)

Furthermore, Elshamy (2019) reflects on his ethical obligation to cover the Ebola epidemic in 2014 despite the health risks to himself. He argues that photojournalism as a tool and medium bears the potential to bring attention to various African crises and human rights abuses that raises donor incentives or immediate government action. A photo, thus, becomes the connection between potential donors and intended beneficiaries.

The following section brings up some ethical dilemmas associated with humanitarian photography and fundraising campaigns. I also give examples of ways I have engaged the public about albinism and what dilemmas I have faced.

5.2.1 Ethical Dilemmas

Following the viral spread of the images and story of Alan Kurdi, the Swedish Red Cross saw a significant rise in numbers and amounts of donations until five weeks after the photo's appearance. Thereafter, numbers and amounts of donations dropped to the same levels as before the spread of the photo (Slovic *et al.*, 2017). The authors of the article (Slovic *et al.*, 2017) name this phenomenon "the iconic victim effect" (followed later by "psychic numbing" and "compassion fade"), indicating that a portrait of a single victim, in comparison to statistical victims, triggers emotions that encourage donor giving among many people (similar to the identifiable victim effect). However, as the public's memory of the photo faded, so do donations even though the crisis continues.

The photo of Alan raises several ethical questions regarding the subject: it is not just a child, but a child who is dead. Indeed, the photo sparked empathy which led to increased donations, but was it ethically right to share the photo? How did the viral spread affect the grieving relatives of Alan? (see Morelli, 2015). Even further, can a violation of ethical standards be justified if it results in significant donor giving which could save many lives? If a photo does not result in any donations, we might perhaps answer "no" to such a question. Maybe we would also say no if it only led to 1,000 USD. But if the number of donations rose to 10,000 USD or perhaps, even 50,000 USD, would we then start to reconsider our ethical standpoint? Imagine a photo that reveals the situation of one vulnerable individual that is so powerful that it results in donations that could save the lives of hundreds of people in a humanitarian crisis. Would it be okay to publish such a photo? Would it still be okay if only one life would be saved? Or do we value lives differently?

Visual images are crucial tools in my work to raise albinism awareness and engage the public about Sr. Martha and her work for children with albinism. However, using photos and videos as a storytelling strategy is not unproblematic as Sr. Martha works with children who cannot give their consent to be photographed. Additionally, children with albinism (CWA) are a vulnerable group and at risk of being attacked because of instrumentalising rumours. Subsequently, it is even more important to consider how they are portrayed. If they can be identified in photos and videos, how to ensure they are protected? How to avoid exotifying their bodies and exploiting them?

I have followed Swedish legislation on photographing children to avoid producing offensive photos or acting in a harassing way (SFF, 2013; Familjens Jurist, 2019). The data protection law GDPR, adopted in the EU in 2018, regulates the handling of personal information (e.g., photos can contain personal data) (Kasteva, 2018; ICO, 2022; Koch, 2022; Wolford, 2022). Journalistic, artistic, literary, or academic creation are exempted from the GDPR law in Sweden because of the fundamental law on freedom of expression and the freedom of the press act (Fröderberg, 2018; SFF, 2018; Wessel, 2018; David, 2019). I consider my work to fall under three of these exempted categories.

5.2.1.1 Children

I post a picture of a girl’s half face to Instagram and Facebook and write: “I want to post the picture of Small S. I want you to see her face, see the drops of sweat under the sunhat, see a child. But I must protect her integrity. Sr. Martha must protect her life” (translation from a Facebook post, January 17, 2022, see Román (2022) and Figure C1 in Appendix C).

The portrayal of a child’s struggle (Fehrenbach and Rodogno, 2015:14) often affects the observer at a deep emotional level. At times leading to unforeseen but often much needed collective responses and social change. Marta Zarzycka (2015) writes about why, especially, children’s faces have become “a visual trope” in humanitarian marketing strategies that reflect universal human rights.

> The expressivity of children's faces, their presumed lack of artifice, the softness of their skin, and pleasantness of their features all translate well into the photographic. The acute disturbance of our visual pleasure when the beauty of a child's face is destroyed – by scars, bandages, cuts, and burns – makes news stories and aid appeals seem both urgent and ethically transparent (Zarzycka, 2015:29).

Whether exposure to a happy or sad victim in images generates prosocial behaviour depends on the characteristics of donors and the message appeal. Research on the topic has shown quite conflicting results. Some scholars argue that a sad emotional expression (Small and Verrochi, 2009) of a victim increases the observer's sympathy, hence willingness to donate. At the same time, other findings suggest that just exposure to sad images might cause an emotion of hopelessness, while too happy images make the viewers question if their help is needed (Septianto and Paramita, 2021:92;94).

In their study on psychological involvement, perceived efficiency and donor behaviour, Cao and Jia (2017:68) explain these conflicting arguments for facial expressions. Donation intentions resulting from exposure to a sad or happy image depend on the donor's psychological involvement with charities. Moreover, individuals who already have or are involved with charitable activities tend to donate when exposed to a happy (versus sad) image. The reverse is true for individuals with no previous psychological involvement. Their donation intentions increased when seeing a photo of a sad person. According to the authors, an involved person needs to know that her contribution will matter, which a positive image signifies. A negative photo can instead discourage her (Cao and Jia, 2017). Meanwhile, an individual not familiar with charities often gets convinced or feels the urge to contribute when seeing a sad (versus happy) photo. In that way she reduces the negative emotions triggered by the image.

Septianto and Paramita (2021), on the other hand, advice for a mixed emotional appeal that combines a happy victim image with a strong and sad message appeal to encourage time and money donations, which the authors refer to as "prosocial behaviour". Various scholars have manipulated other factors – such as (i) "similarity- and guilt-based charity appeals" (van Rijn, Barham and Sundaram-Stukel, 2017); (ii) physical appearance of recipients (Cryder, Botti and Simonyan, 2017; Carvalho, Hildebrand and Sen, 2019) and (iii) donors' sociodemographic characteristics (Shier and Handy, 2012) – in experiments to explore the linkages to charity giving.

The widespread focus on child-centred humanitarian photography (Fehrenbach and Rodogno, 2015; Zarzycka, 2015; Bhati and Eikenberry, 2016) in charity appeals and social justice campaigns to remind people about their social responsibility raises a set of ethical concerns for the identity and voice of the children portrayed. This is also true in cases when images illustrate hope (e.g., empowerment) rather than despair. Zarzycka (2015:36) writes that sponsored children do not get the chance or space to tell their story – from their point of view – without the expectation of pleasing the donor. In a unique study, Bhati and Eikenberry (2016:35) show that most destitute children – who are beneficiaries of four Indian NGOs – preferred to be portrayed as happy with clean clothes. Yet, for fundraising purposes images should also represent their hardship and struggles. Meanwhile, NGO managers and photographers testified about the challenges of creating engaging content that portrays "beneficiaries in a good light while also showing "need" to donors" (Bhati and Eikenberry, 2016:31). Alarming is that children seldom are aware of the reason for a photo shoot and that their photos will be shown in future fundraising campaigns (Bhati and Eikenberry, 2016:39) which adds to the ethical dilemmas of informed consent and the tendency of objectifying children in humanitarian photography.

One way to walk around these ethical concerns is to avoid using photos and let words paint a descriptive picture of the situation. But one should not ignore the fact that there are even ethical issues in verbal storytelling. As people began donating money to Sr. Martha through me, I felt responsible of showing how their donations had been used – photos are a powerful and convincing tool. Yet, I wanted to respect the integrity and dignity of the children and decided not to upload pictures that showed their faces. In cases when I could not crop images, I placed a heart emoji to cover their face.

I made a short documentary out of videos I had recorded during my participation in preparing and celebrating Christmas 2021 with Sr. Martha and the children. The movie features clips of children sweeping the inner yard, peeling garlic cloves, and patiently waiting for the bus to drive them to the church on Christmas day. But the children's central involvement in the movie made it problematic to upload it online. Once on the Internet, always on the Internet. The digital permanence made me question if I still would have the right to post the documentary even in the unlikely event that Sr. Martha and all guardians would give their consent for the children's participation. If the film got into the wrong hands, was there a risk that people with bad intentions would try to track the location of Sr. Martha or individual children to harm them? The documentary showed the reason for Sr. Martha's engagement despite challenges in a touching and informative way. I, therefore, contemplated blurring out the children's faces, but it would affect the message and I decided not to post the video online.

In May 2022 I got an opportunity to hold a public lecture at the Uppsala City Library for youths on how one can create engaging digital content for social media. I drew on my experience of storytelling to create albinism awareness and – with permission from Sr. Martha – screened the documentary. We had agreed that displaying the short movie at a public event would avoid the issue of permanence associated with the digital sphere. In addition, we considered instrumentalising rumours to be close to nonexistent among the Swedish audience. As such, there was a low risk the movie screening in Sweden would cause harm to CWA in Tanzania.

I have tried my best to uphold my ethical standpoint regarding the photos I post, but what emotions a photo causes are subjective to the observer – I might perceive a cropped portrait to respect the child's integrity (Figure C2) while another might find the cropping to be grotesque (Figure C3). The cropped image zooms in on a body part, which may add to the objectification of people with albinism. How one perceives a photo also depends on where we get exposed to the photo – on the screen of one's phone? in a frame at an exhibition? I stumbled upon this while preparing a photography exhibit of my ethnographic work at a restaurant called Don Felice, located at Kvarnholmen in Stockholm in late August 2022. Photos published on my social media accounts are not guaranteed to work in the exhibition. Likewise, a close-up portrait might work in a large gallery, but not in a restaurant. To cite Susan Sontag (2003:68) from her book *Regarding the Pain of Others*: "A photograph seen in a photo album or printed on rough newsprint… means something very different when displayed in an Agnes B. boutique".

The goal of the exhibit was to raise albinism awareness. Therefore, photos had to catch the attention and curiosity of the observer in hopes that she or he would read a short text describing the specific moment captured or a more general challenge experienced by PWA. I had to remind myself that people visiting the restaurants did not know about my work and presumably had low albinism awareness. With that in mind, what photos would be most powerful to convey the message – cropped images that do not reveal the child's identity or uncropped images that invite the observer to "meet" a human being? In the end, I chose to use uncropped imageries for the exhibition because they are illustrative and in the context of an exhibition: less objectifying than zoomed-in pictures. Since the photos are displayed in a physical venue in Sweden, as opposed to online, the risk of them spreading to harm the children is very low.

While reading about ethical dilemmas with child-centred humanitarian imagery, I questioned my work even more. Especially one post is ethically questionable. It is the photo, together with the text that makes it too revealing. By the time of writing, it did not cross my mind as Sr. Martha so openly told me about the boy who had been maltreated and abandoned as a child. I felt guilty about exposing the child and his story a few months later. I have now deleted the post from my Instagram and Facebook, but I cite parts of it here for the purpose of being transparent about the ways I have talked about people with albinism and sometimes failed to keep up with the ethical standards:

> Martha tells how she found you: behind the tarpaulin where the food was cooked, surrounded by smoke from the coal. Pissed-down pants. The other children played while you were forced to a place where you could not be seen; hidden […] You do not travel home during the school holidays because your family does not want you there. Your mother only stays a couple of minutes the few times she visits you at Sr. Martha's home […] Your father refused you to get circumcised (common among Christians, Maasai and Muslims in Tanzania). To not be circumcised as a man is a great shame; you remain a boy in the eyes of others and are excluded from social events. (Translation from a post published 20 March 2022)

It is the last part that makes me re-read what I posted online with disgust and disappointment over my own actions. Telling the public about the time of a boy's circumcision is too exploitative. I do not defend it, but I remember why I wrote it. At first, I felt uncomfortable when Sr. Martha so openly talked about circumcision as it is an uncommon practice in Sweden – not necessarily a topic of taboo but considered very private. Nevertheless, as she spoke and explained male circumcision, I understood that it is perceived differently in Tanzania than in Sweden. And with that understanding of cultural differences, I also understood the width of neglect the boy had experienced from his parents, especially his father.

Humanitarian aid, assistance, and work rest on their ability to value the integrity, dignity, and rights of humans despite situations and circumstances but depend heavily on charity giving. Thus, INGOs must build and maintain donor trust to continue their work. At times, the goal to prove to be trustworthy and accountable conflicts with the values of the INGO (ICO, 2022). Matthew Sherrington (2015 cited in Bhati and Eikenberry, 2016:39) put it well:

"How can the need that provokes a response be shown while representing the dignity and agency of poor people?".

5.2.1.2 Stereotypes

The authors Fehrenbach and Rodogno argue that "humanitarian imagery is moral rhetoric masquerading as visual evidence. As such, humanitarian photography was, and is, politically and morally charged terrain" (Fehrenbach and Rodogno, 2015:6).

One should not ignore that humanitarian photography of human suffering risks reinforcing stereotypes of the poor and privileged: developed and less developed nations. Undoubtedly hierarchies of power and status are present as soon as one captures an image – who is the one having access to the technology, who is the photographer, who gets photographed, and for what reason? One could ask how visual images and media coverages of African countries reinforce or challenge pre-existing western perceptions about the continent. There is a risk that news about human rights violations and simplified explanations add to a general negative assumption about Africa as a "hopeless", "undeveloped", and "crisis-ridden" continent. Except for occasional of positive coverage, "Afropessimism" (Wright, 2018:8) often influences journalists who write about Africa: "[the] homogenizing, negative and racist forms of news are often claimed to inflict serious harm on African people: undermining their self-esteem, and preventing international recognition of their diverse political systems and cultures" (Wright, 2018:8). Some argue the negative representation of Africa through images is exploitative and may even be labelled pornographic because it is the body rather than the thoughts of the subject which is being captured (Wright, 2018b:9).

I have found myself caught in the dilemma of representation as I speak to a western audience about the severe stigma and violence PWA in Africa face because of myths and instrumentalising rumours. At times, I have chosen simplifications to shed light on the issue and catch the public's attention and engagement, but at the expense of representing and discussing African cultures, religions, practices, and behaviour free of ethnocentrisms. It is especially true for the times I explained mutilations and killings as motivated by witchdoctors and driven by people's belief in witchcraft. As shown, this is to some extent true, but the reality is far more complex with an integration of varying beliefs. Simplified representations risk reinforcing the image of African societies and countries as "backward" and "less developed". It is why it felt even more urgent to invent and use the term "instrumentalising rumours" instead of witchcraft belief.

5.3 Public Responses

After screening the short documentary at Uppsala City Library, a girl from Somalia bravely talked about the time she met her friend's cousin with albinism in the south of Stockholm. She described how she had laughed when she saw the cousin and claimed that he could not possibly be from Somalia, given his white skin colour. The boy told the girl about his condition, albinism, of which she was unaware (from field diary, 18 May 2022).

The following sections review some public responses to the stories I told about albinism and Sr. Martha to raise awareness and create engagement. I identify and categorise four types of responses: (A) social media interactions; (B) donor giving; (C) buying one Albinism Awareness product and (D) participating in a public lecture, a webinar or an art exhibition.

People interact with Instagram Stories and posts (i.e., liking, commenting, sharing, answering polls and questionnaires) I share on Instagram and Facebook about albinism and more specifically about Sr. Martha's work and situation. The social media platforms have been essential for me to (a) tell stories about people with albinism and (b) spread basic knowledge about the condition such as the vision impairment, the high risk of developing skin cancer and common types of discrimination.

I learned that Instagram Story was ideal for educational posts to pedagogically explain albinism and track incoming funds. I began updating my followers on how much money we raised for sun lotions and sun hats for children with albinism during the first fundraising campaign, after publishing my first Instagram and Facebook post about Sr. Martha. Within one week, we had raised 13,691 SEK (1,362 USD). I had already created informative and interactive Instagram Stories about albinism a few days before I introduced my social media followers to Sr. Martha for the first time. It might explain why 46 people showed solidarity and donated money for the cause of buying sun protecting means – they had been made aware of the health risks associated with albinism

Moreover, it is also possible that the public tracking of incoming funds on Instagram motivated people to donate specific amounts to pass a set goal which could explain why so many contributed. I did not track donations as extensively in the second fundraising campaign compared with the first (5 versus 32 Instagram Stories). Subsequently, there was a difference of 9,791 SEK (867 USD[18]) in raised funds. I kept this in mind as I launched the third fundraising

---

[18] Converted from SEK to USD, 25-09-2022.

campaign in May 2022. I publicly kept track of raised funds by posting 32 Instagram Stories. Subsequently, 10,230 SEK (906 USD) was raised to support Sr. Martha and CWA during the summer holidays (see Appendix A, Table A1). In total, 84 people have donated a total amount of 32,121 SEK (2,844 USD). Fewer people donated to the third fundraising appeal compared to the first one. However, the amount of donations per person rose in the third campaign, from an average of 291 SEK (26 USD) in the first campaign to 465 SEK (41 USD). When asking one donor why they had contributed to all three campaigns, they told me:

> Your stories about the vulnerability of these people whose [condition] is minor in our society but over there is a dangerous "disease" makes [me] want to help these children and young people who have been forgotten. Without you, I would not have known so much [about the situation]. (Translation from donor's message, 8 April 2022)

The texts I published on Instagram and Facebook affected readers on an emotional level who responded in various ways. Some came to comment on the posts (what I refer to as social media interaction, public response type A) while others donated money (referred to as donor giving, type B). The Christmas fundraising campaign, like the first campaign, was initiated by one follower who had read my post describing the situation for Sr. Martha and the children. The follower, and others who joined with her, contributed for the cause of giving Sr. Martha an opportunity to celebrate Christmas with the children.

Two weeks pass the Christmas celebrations, and I lie on one of my two Queen-sized beds while being on the phone with Sr. Martha. It shocks me how calm she is when she tells me that she, her husband, and the children are fine, even though they have no food. I sit up, what? no food? She tells me that yesterday, she put 15 children to bed without a single meal of food. I withdraw 800 SEK (71 USD[19]) left from the Christmas fundraising campaign and give it to her.

On Instagram and Facebook, I expressed how wonderful it was to be able to immediately help Sr. Martha because of the great generosity people had shown the weeks before. That short post of gratitude encouraged people to contribute even more, a total of 3000 SEK (266 USD) was raised though my intention with the post was not to collect donations.

---

[19] Converted from SEK to USD, 25-09-2022.

Likewise, a post that does not yield direct donor giving, might indirectly trigger the empathy of a person to give another time or during a specific fundraising campaign. For example, I write about Small S to describe the situation of a vulnerable child, not to encourage donor giving. One follower commented:

> They really grab me, your words. Say hello to Small S from me that... that someone in a land far, far away now knows she exists. That I think of her and wish her all the best and that a beautiful soul can be one of the most valuable things a person can have. (Translation from post published 17 January 2022, see Román, 2022)

The same follower began asking me about Small S when I shared a new story from my observations or a thought regarding the many forms of discrimination people with albinism face. As I launched the third fundraising campaign to support Sr. Martha during the summer (2022), the person donated for the first time. Evidently, Small S was still on her mind because she wrote "say hello to Small S and Martha from us" (Translation from a donor's message, 8 June 2022).

I realised after the first fundraising campaign that few people knew about albinism, let alone the difficulties people with albinism face every day in their lives. I had witnessed the power of strangers coming together for one cause and it was beautiful to see how engagement spread amongst my followers like waves on the water surface. With this realisation and a strong devotion to continue supporting persons with albinism, I looked for other ways to reach people who had engaged with my posts but not donated money. Maybe people would consider supporting Sr. Martha if there were other options than donating money? I started to print my artwork on tote bags and sold these to raise funds and increase albinism awareness. Later, I began sewing makeup bags and coin purses out of the fabric. As a result, 70 individuals have bought a total of 117 tote bags and 27 makeup bags and coin purses, resulting in a profit of 12,764 SEK (1,130 USD)[20]

In addition to these activities to raise funds, I have tried to also raise albinism awareness outside the digital sphere. I have screened the short documentary for a youth group and in two classes at Uppsala University and set up a photo exhibition at a local restaurant in Stockholm.

The Saturday 27th of August (2022) is a warm day. Tomorrow, we will wake up and realise that it was the last summer day for this year, but for now, the sun is shining, the sweat

---

[20] Note that this does not include profit to donate from 2022.

is pouring, and I welcome 35 people to my exhibition about my time in Tanzania, at the restaurant Don Felice. “I would like to buy this photo”, he says, still looking at the picture of Sr. Martha’s late mother.

Carrying out events in the physical sphere have been important to (a) raise albinism awareness amongst people that do not follow me on social media and (b) analyse how public responses differ depending on the platform. Perhaps the most obvious difference, although people at physical events showed a genuine interest and concern for PWA and Sr. Martha’s situation by asking questions, only a few expressed or showed a will to financially support her. In contrast to some of my followers, who donate money to Sr. Martha because they trust and know me, I am a stranger to the audience at physical events. The lack of trust and my presence during the ongoing exhibition under six weeks might explain why there have been fewer initiatives. However, I also believe the consistent digital storytelling has added credibility to my stories about the difficulties for PWA and Sr. Martha. Furthermore, there has been time for my followers to process information and make an informed decision on whether they want to support or not.

Finally, the webinar held in June 2022 gathered 19 individuals who had shown solidarity with Sr. Martha’s work or curiosity to learn more about albinism. Many participants asked questions after watching the short documentary. It is the first time Sr. Martha meets foreigners in this way to talk about her experiences and difficulties. The discussion evolves around financial challenges, why some CWA cannot go home during school breaks and the importance for them to pass their education to eventually sustain themselves. Before we are to finish the meeting, I tell Sr. Martha that many people want to support her, and together we have collected over 8,000 SEK (800 USD) so she can give a shelter to 19 children over the summer holidays. She gasps for air and her surprise and relief cannot be mistaken. I look at the rest of small squares filled with faces on my laptop screen and notice that not only Sr. Martha cries, but several of us.

Chapter 6. Conclusion

This thesis has sought to explore how one tells a story about people with albinism that will engage a western public without violating ethical standards. I have drawn on my ways of using social media to raise albinism awareness and reflected on the public responses it led to and some ethical dilemmas that arose with the storytelling. At the foundation of the thesis lies ethnographic fieldwork conducted in northern Tanzania during two research phases totalling seven months. I have observed the work of one woman with albinism, Sr. Martha, on her mission to support and shelter children with albinism. The thesis provides the reader with detailed descriptions that illustrate discrimination and life threats facing people with albinism (PWA) in many parts of sub-Saharan Africa.

As shown in Chapter 3, children with albinism face several obstacles to accessing education. Low albinism awareness amongst teachers often means there is no option for adaptive learning. Subsequently, children and youths with albinism are lagging behind their peers, which sometimes negatively affects their motivation to complete their studies. I described a conversation I had with a teenager in secondary school and a phone call Sr. Martha received from a mother to illustrate the lack of awareness in the schools regarding vision impairment and skin cancer prevention.

Because of the lack of melanin in skin cells, PWAs are prone to developing skin cancer, especially for people living closer to the equator. It is thus essential to avoid exposure to the sun's ultraviolet rays by being inside, using sun lotion and wearing thick clothes and sunhats to prevent nonmelanoma skin cancer. Sadly, few persons with albinism can choose to work inside because of the scarcity of employment and the fact that subsistence farming is often only available. At the same time, it is difficult for PWAs to access the job market when some lack the education needed because of discrimination in schools. Perhaps more disturbing, employers might avoid hiring a person with albinism because of widely held misbeliefs.

Unfortunately, physical and psychological violence targeting PWA is not uncommon and is often caused by misbeliefs and myths regarding albinism. At times the perpetrators might be close relatives, as apparent in the study of Aborisade (2021) and testimonies from Sr. Martha. This topic brought me to reflect on the emotional well-being of children and adults with albinism. In Chapter 3, I recalled an interview with Sr. Martha where she told me how she tried to commit suicide in her early twenties. It became apparent that she copes with trauma and challenges by drawing on her understanding of a Christian life and vocation, something that made me wonder how religion and spirituality affect the mental wealth of persons with albinism.

In Chapter 4, I argued that myths, in combination with socioeconomic and normative factors, give rise to instrumentalising rumours. A term I further defined as the spreading belief that the body or parts of the body from a person with albinism can be used as an instrument to cause wealth and success, cure HIV/AIDS and break bad omens. More generally, I suggested that we conceive of instrumentalising rumours as stories that ascribed to people a utility that can be appropriated by ignoring their human dignity. Other reasons to use the invented term instead of language about witchcraft beliefs – as has often been the case when talking about attacks and killings – are to: (a) avoid the lack of specificity and oversimplification of blaming witchcraft; (b) consider the coexistence of religious and traditional beliefs in contemporary SSA and (c) limit the risk of reinforcing colonial stereotypes. The more neutral and analytical term, "instrumentalising rumours", could make it easier to bring together stakeholders from across African societies to address the stigma against PWA.

Although my focus has been on a particular Tanzanian city, ill-treatment and stigmatisation are well-documented and studied across the continent. It is moreover not a question of whether Africans with albinism face social stigma or not, but to what extent.

The research question – how does one tell a story about people with albinism that will engage the western public without diminishing their dignity or violating ethical standards? – guided the structure for Chapter 5. Theories on donor giving, communication strategies and the power and ethical dilemmas of humanitarian photography were presented. Further, the chapter drew on the six ways I told stories (Instagram Stories, Instagram posts, Facebook posts, photo exhibition, public lectures, and a webinar) and the four types of public responses they led to (social media interaction, donor giving, buying a product, and actively participating in a public lecture webinar or art exhibition).

I assessed the strategies used and what outcomes they led to. In doing so I also brought up some ethical dilemmas I encountered throughout the project. Amongst those: what images to use, in what setting, and with what message? These dilemmas got ever more complex considering that video clips and photos portray children who not only are vulnerable because of their age, but because of instrumentalising rumours about children with albinism. Moreover, will a violation of ethical standards be justified if it results in significant donor giving, money which could save many lives?

Turning into the question of further research, it could be valuable to explore whether "instrumentalising rumours", as a concept, is useful or not. This could be done by investigating the meaning of “witchcraft” in different cultural and geographical settings. For instance, by conducting a discourse analysis in combination with quantitative research to grasp the perceptions of a large number of people. Participatory Action Research and in-depth interviews could be a part of this research. What do experts, believers in religious and traditional beliefs and people with albinism think about the term “instrumentalising rumours”?

Another area that needs the attention of scholars and students is the emotional well-being of persons with albinism. Skin cancer dominates the field of health-related issues for the albinism community. Several local and international NGOs also work to inform and prevent skin cancer. Meanwhile, there is a scarcity of literature on vision impairment as well as psychological well-being. For the latter, it could be interesting to explore the roles of interfaith networks to address the experiences of stigma and marginalisation. How can religious institutions and leaders become role models in treating PWA as equals?

There is a risk that human rights violations against people with albinism, get perceived as a problem isolated to Africa because of the hundreds of attacks and killings peaking in the late 2000s. Indeed, much literature on albinism deals with an African context. It is, therefore, crucial to also reach out to PWA elsewhere. For instance, what are the attitudes towards PWA in Sweden, and what discrimination do they face?

With regards to the main focus of this thesis – storytelling to engage the public about humanitarian situations without diminishing human dignity and violating ethical standards – what could future studies entail? Here, I suggest a comparative analysis of ethical standards that considers journalistic, academic, and artistic (e.g., photography) work from different organisations and instances to ask: what range of portrayals might be considered unacceptable? What are the possible circumstances, if any, under which a competing ethical goal (e.g., to raise awareness, raise money, persuade a parliament to launch an investigation) might override a particular ethical standard? One could think here about the picture of young Kim Phuc: a naked child who is on fire (Figure B3). The image is completely unacceptable according to most ethical standards. Yet, many would agree that the photographer Nick Ut was right to take the photo as it spread global awareness about the Vietnamese War. We must be open to the possibility that there might be strong, competing arguments which override certain institutional ethical guidelines. Another question is what are the differences in this arena between academic and journalistic work?

A decision tree could be developed to help explore different cultural contexts and what kind of portrayal might be experienced as diminishing someone’s dignity. Perhaps the ethical decisions should largely follow the preferences of the individuals in question: some may be happy to have their photos published while others may be horrified. In this sense, dignity is not just contextual and situational but individual and biographical.

Telling stories is in one way very much an art, but it is also becoming a science, as we have seen from various studies on donor giving and fundraising appeals. Further studies of different dimensions of storytelling will add to the knowledge of telling a story that will engage the public about humanitarian situations.

In his classic study of impoverished farmers during the 1930s, James Agee wrote that he sought “to recognise the stature" of the individuals he was meeting and living amongst. (Agee and Evans, 2001 [1941]). In the same vein, Sr. Martha – speaking of the children in the short documentary – said that we must recognise that “they are very important people”.

One of those very important people is Small S. I posted a picture showing only half her face, the day Sr. Martha told me about the night three men had arrived on motorbikes in the neighbourhood with a box, asking for the “white girl”. I had met Small S for the first time a few weeks earlier. She had laughed at my long nails, plaited my hair, and kept asking me to take photos of her. She had given me half of her biscuit the day I hid in a room when I was exhausted and drained. And here I am, sitting by my window in a Stockholm suburb, imagining how Small S hid for her life under her grandmother’s bed. The box. I cannot stop thinking about the box. What would the attackers have done with the box if they had found Small S? She is a very important person to me, and I hope to others.

Bibliography

AAN (2022) *Grave Desecration - Malawi*, *African Albinism Network*. Available at: https://www.facebook.com/africaalbinismnetwork/photos/a.182555799263214/1205229563662494 (Accessed: 30 August 2022).

Aborisade, R.A. (2021) '"Why Always Me?": Childhood Experiences of Family Violence and Prejudicial Treatment against People Living with Albinism in Nigeria', *Journal of Family Violence*, 36(8), pp. 1081–1094. Available at: https://doi.org/10.1007/s10896-021-00264-7.

Agee, J. and Eveans, W. (2001) *Let Us Now Praise Famous Men: Three Tenant Families*. Mariner Books.

AjiraLeo (2022) *Tanzania (MISHAHARA) Salary Scale Range 2021/2022*, *Ajira Leo*. Available at: https://www.ajiraleo.com/2020/10/teachers-salary-scale-range-check-here.html (Accessed: 8 July 2022).

Alyson., M, C. (2007) 'Situating Anti-Victim Discourse', in *The Cult of True Victimhood: From the War on Welfare to the War on the Terror*. Stanford: Stanford University Press, pp. 1–20.

Baloyi, T. (2022) *Ritual Murder: Bald Man's Head Decapitated for 'Gold' in Mozambique*, *The South African*. Available at: https://www.thesouthafrican.com/news/ritual-murder-bald-mans-head-decapitated-for-gold-in-mozambique/ (Accessed: 25 September 2022).

BBC (2009) 'Death for Tanzania Albino Killers', *BBC News*, 23 September. Available at: http://news.bbc.co.uk/2/hi/africa/8270446.stm (Accessed: 16 April 2022).

BBC (2015) *Tanzania Albino Killers Sentenced to Death*, *BBC News*. Available at: https://www.bbc.com/news/world-africa-31748400 (Accessed: 24 September 2022).

BBC (2017) *Mozambique Police Warn Bald Men After Ritual Attack*, *BBC News*. Available at: https://www.bbc.com/news/world-africa-40185359 (Accessed: 25 September 2022).

Benyah, F. (2017) 'Equally Able, Differently Looking: Discrimination and Physical Violence against Persons with Albinism in Ghana', *Journal for the Study of Religion*, 30(1), pp. 161–188. Available at: https://doi.org/10.17159/2413-3027/2017/v30n1a7.

Bhati, A. and Eikenberry, A.M. (2016) 'Faces of the Needy: The Portrayal of Destitute Children in the Fundraising Campaigns of NGOs in India: Faces of the Needy', *International Journal of Non-profit and Voluntary Sector Marketing*, 21(1), pp. 31–42. Available at: https://doi.org/10.1002/nvsm.1542.

Brocco, G. (2016) 'Albinism, Stigma, Subjectivity and Global-Local Discourses in Tanzania', *Anthropology & Medicine*, 23(3), pp. 229–243. Available at: https://doi.org/10.1080/13648470.2016.1184009.

Burke, J. (2010) 'Mother Describes How Her Albino Child Was Killed', *Albinos in Tanzania*, 25 July. Available at: http://albinos-in-tanzania.blogspot.com/2010/07/mother-describes-how-her-albino-child.html (Accessed: 16 April 2022).

Cambridge Dictionary (2022a) 'Cambridge Dictionary: Engage', *Cambridge Dictionary (Online)*. Available at: https://dictionary.cambridge.org/dictionary/english/engage (Accessed: 26 October 2022).

Cambridge Dictionary (2022b) 'Rumour', *Cambridge Dictionary (Online)*. Available at: https://dictionary.cambridge.org/dictionary/english/rumour?q=rumours (Accessed: 1 September 2022).

Cao, X. and Jia, L. (2017) 'The Effects of the Facial Expression of Beneficiaries in Charity Appeals and Psychological Involvement on Donation Intentions: Evidence from an

Online Experiment', *Non-profit Management and Leadership*, 27(4), pp. 457–473. Available at: https://doi.org/10.1002/nml.21261.

Carvalho, S.W., Hildebrand, D. and Sen, S. (2019) 'Dressed to Impress: The Effect of Victim Attire on Helping Behaviour', *Journal of the Association for Consumer Research*, 4(4), pp. 376–386. Available at: https://doi.org/10.1086/705034.

Chronicle (2022) *Getting to Know Miss Albinism Zimbabwe, Angie Dube*, *Chronicle*. Available at: https://www.chronicle.co.zw/getting-to-know-miss-albinism-zimbabwe-angie-dube/ (Accessed: 24 September 2022).

Club of Mozambique (2022) *Teenager with Albinism Killed for Body Parts in Mogovolas, Mozambique*, *Club of Mozambique*. Available at: https://clubofmozambique.com/news/teenager-with-albinism-killed-for-body-parts-in-mogovolas-mozambique-217846/?fbclid=IwAR0blJnFtCIbH7Bshgi3bscI_TXVIAqiBOLPCx564GfwVEXIxbrvoBx8wB0 (Accessed: 30 August 2022).

Cryder, C., Botti, S. and Simonyan, Y. (2017) 'The Charity Beauty Premium: Satisfying Donors' "Want" versus "Should" Desires', *Journal of Marketing Research*, 54(4), pp. 605–618. Available at: https://doi.org/10.1509/jmr.14.0658.

Daniel Ikuomola, A. (2019) 'Beyond Asexualization: Narratives of Sexual Objectification of Persons with Albinism in Nigeria', *Issues in Ethnology and Anthropology*, 14(1), pp. 223–245. Available at: https://doi.org/10.21301/eap.v14i1.9.

David, L. (2019) *Fotografier, GDPR och hantering av personuppgifter*, *David Lagerlöf Photography and Communications AB*. Available at: https://www.fotograflagerlof.se/gdpr (Accessed: 30 August 2022).

Dghar, M. (2022) 'Human trafficking / Buried alive: Tanzania's Albinos Pay the Price for Superstition', *enact*, 17 March. Available at: https://enactafrica.org/enact-observer/buried-alive-tanzanias-albinos-pay-the-price-for-superstition (Accessed: 16 April 2022).

Ein-Gar, D. and Levontin, L. (2013) 'Giving from a Distance: Putting the Charitable Organization at the Centre of the Donation Appeal', *Journal of Consumer Psychology*, 23(2), pp. 197–211. Available at: https://doi.org/10.1016/j.jcps.2012.09.002.

Elshamy, M. (2019) 'Photojournalism and Human Rights in Africa: Stories from the Field', in R. Adeola et al. (eds) *The Art of Human Rights. Commingling Art, Human Rights and the Law in Africa*. Springer.

Engstrand-Neacsu, A. (2009) *Defending Albinos' Rights to Life*, *reliefweb*. Available at: https://reliefweb.int/report/burundi/defending-albinos-rights-life (Accessed: 17 April 2022).

Ero, I., Muscati, S. and Annamanthadoo, I. (2021) *People with Albinism Worldwide*. Albinism Worldwide (Report number: A/74/190). United Nations General Assembly. Available at: https://www.ohchr.org/sites/default/files/Documents/Issues/Albinism/Albinism_Worldwide_Report2021_EN.pdf.

Fallot, R.D. and Blanch, A.K. (2013) 'Religious and Spiritual Dimensions of Traumatic Violence.', in K.I. Pargament, A. Mahoney, and E.P. Shafranske (eds) *APA Handbook of Psychology, Religion, and Spirituality (Vol 2): An Applied Psychology of Religion and Spirituality.* Washington: American Psychological Association, pp. 371–387. Available at: https://doi.org/10.1037/14046-019.

Familjens Jurist (2019) *Är det lagligt att filma barn utan föräldrarnas medverkan? Familjens Jurist*. Available at: https://www.familjensjurist.se/fraga-juristen/ovrigtannat/ar-det-lagligt-att-filma-barn-utan-foraldrarnas-medverkan/ (Accessed: 29 August 2022).

Fehrenbach, H. and Rodogno, D. (2015) ‘Introduction. The Morality of Sight: Humanitarian Photography in History’, in H. Fehrenbach and D. Rodogno (eds) *Humanitarian Photography - A History*. Cambridge: Cambridge University Press, pp. 1–21. Available at: https://doi.org/10.1017/CBO9781107587694.001.

Forner, F. and Ortiz, F. (2018) *Living with Albinism in Mozambique*, *Equal Times*. Available at: https://www.equaltimes.org/living-with-albinism-in-mozambique?lang=en#.Yw8ygy8RpQI (Accessed: 31 August 2022).

Fröderberg, M. (2018) *Så påverkas du som fotograf av GDPR*, *Fotosidan*. Available at: https://www.fotosidan.se/cldoc/lagochratt/sa-paverkas-du-av-gdpr.htm (Accessed: 30 August 2022).

Gall, T.L. and Guirguis-Younger, M. (2013) ‘Religious and Spiritual Coping: Current Theory and Research.’, in K.I. Pargament, J.J. Exline, and J.W. Jones (eds) *APA Handbook of Psychology, Religion, and Spirituality (Vol 1): Context, Theory, and Research.* Washington: American Psychological Association, pp. 349–364. Available at: https://doi.org/10.1037/14045-019.

Geertz, C. (1973) ‘Thick Description: Toward Interpretive Theory of Culture’, in *The Interpretation of Cultures*. New York: Basic Books, Inc., Publishers, pp. 3–33.

Genetic Alliance (2009) *Understanding Genetics: A New York, Mid-Atlantic Guide for Patients and Health Professionals*. Washington (DC): Genetic Alliance. Available at: https://www.ncbi.nlm.nih.gov/books/NBK115561/ (Accessed: 12 March 2022).

Gordon, A. (2007) ‘Population, Urbanization, and AIDS’, in A. Gordon and D. Gordon (eds) *Understanding Contemporary Africa*. 4th ed. Boulder: Lynne Rienner Publishers, Inc.

Gordon, A. and Gordon, D. (2007) ‘Introduction’, in A. Gordon and D. Gordon (eds) *Understanding Contemporary Africa*. 4th ed. Boulder: Lynne Rienner Publishers, Inc.

Hairapetian, M. (2014) *Albinos Don’t Die, They Just Disappear*, *Fair Planet*. Available at: https://www.fairplanet.org/story/albinos-dont-die-they-just-disappear/ (Accessed: 17 April 2022).

Hodzic, S. (2016) *The Twilight of Cutting: African Activism and Life after NGOs*. 1st edn. University of California Press. Available at: https://doi.org/10.1525/california/9780520291980.001.0001.

Human Rights Careers (2022) *What is Human Dignity? Common Definitions.*, *Human Rights Careers*. Available at: https://www.humanrightscareers.com/issues/definitions-what-is-human-dignity/ (Accessed: 26 October 2022).

ICO (2022) *What Happens When Different Organisations Process the Same Data for Different Purposes? ICO, Information Commissioner’s Office*. Available at: https://ico.org.uk/for-organisations/guide-to-data-protection/guide-to-the-general-data-protection-regulation-gdpr/what-is-personal-data/what-happens-when-different-organisations-process-the-same-data-for-different-purposes/ (Accessed: 30 August 2022).

Imafidon, E. (2017) ‘Dealing with the Other Between the Ethical and the Moral: Albinism on the African Continent’, *Theoretical Medicine and Bioethics*, 38(2), pp. 163–177. Available at: https://doi.org/10.1007/s11017-017-9403-2.

In the Shadow of the Sun (2012). Available at: https://vimeo.com/128231780 (Accessed: 14 June 2022).

Kaberia, J. (2020) *The Danger of Living with Albinism in Highly Superstitious Society*, *Capital FM*. Available at: https://www.capitalfm.co.ke/news/2020/11/the-danger-of-living-with-albinism-in-a-highly-superstitious-society/ (Accessed: 26 July 2022).

Kamurungi, E. and Oketch, B. (2022) *Uganda Launches Action Plan to Improve Welfare of Persons with Albinism*, *Monitor*. Available at:

https://www.monitor.co.ug/uganda/news/national/uganda-launches-action-plan-to-improve-welfare-of-persons-with-albinism-3847480 (Accessed: 8 July 2022).

Kasteva, G. (2018) *Att publicera bilder på barn på sociala medier*, *Lawline*. Available at: https://lawline.se/answers/att-publicera-bilder-pa-barn-pa-sociala-medier (Accessed: 30 August 2022).

Khan, A.W. (2013) *East Africa: A Bewitching Tale of Albinism in Tanzania*, *All Africa*. Available at: https://allafrica.com/stories/201302020131.html (Accessed: 18 April 2022).

Koch, R. (2022) *What is Considered Personal Data under the EU GDPR? GDPR.EU*. Available at: https://gdpr.eu/eu-gdpr-personal-data/ (Accessed: 29 August 2022).

Kwame Harrison, A. (2018a) 'Introduction to Ethnography', in *Ethnography*. Oxford University Press. Available at: https://doi.org/10.1093/oso/9780199371785.003.0001.

Kwame Harrison, A. (2018b) 'Writing Up Research Findings', in *Writing Up Research Findings*. Oxford University Press. Available at: https://doi.org/10.1093/oso/9780199371785.003.0004.

Lane, C. (2022) 'The Work of Getting Organized', *Anthropology News*, 63(1).

LHRC (2021) *Press Release: Condemning the Brutal Murder of a Child with Albinism in Uyui District, Tabora Region*. LHRC (Legal and Human Rights Centre). Available at: https://underthesamesun.com/sites/default/files/Press%20release-%20Brutal%20Murder%20in%20Tabora%20Region%20-%20May%202021%20-%20final%20English.pdf (Accessed: 19 September 2021).

Lund, P.M. (2001) 'Health and Education of Children with Albinism in Zimbabwe', *Health Education Research*, 16(1), pp. 1–7. Available at: https://doi.org/10.1093/her/16.1.1.

Makoye, K. (2015) *Four Sentenced to Death in Tanzania for Killing Albino Teenager*, *Reuters*. Available at: https://www.reuters.com/article/us-tanzania-albinos-idUSKCN0PB5QS20150701 (Accessed: 24 September 2022).

Malone, A. (2009) 'The Albino Tribe Butchered to Feed a Gruesome Trade in "Magical" Body Parts', *Mail Online*, 25 September. Available at: https://www.dailymail.co.uk/news/article-1215949/The-albino-tribe-butchered-feed-gruesome-trade-magical-body-parts.html (Accessed: 16 April 2022).

Manaleng, P. (2021) *Mr and Miss Albinism SA Hope to Change How They Are Viewed*, *New York Times*. Available at: https://ewn.co.za/2021/11/15/mr-and-miss-albinism-sa-hope-to-change-how-they-are-viewed (Accessed: 24 September 2022).

Masanja, M.M., Imori, M.M. and Kaudunde, I.J. (2020) 'Factors Associated with Negative Attitudes Towards Albinism and People with Albinism: A Case of Households Living With Persons with Albinism in Lake Zone, Tanzania', *Open Journal of Social Sciences*, 08(04), pp. 523–537. Available at: https://doi.org/10.4236/jss.2020.84038.

Masina, L. (2019) *Malawi Court Uses Death Sentence to Help Stop Attacks on Albinos*, *VOA News*. Available at: https://www.voanews.com/a/africa_malawi-court-uses-death-sentence-help-stop-attacks-albinos/6173912.html (Accessed: 24 September 2022).

Masina, L. (2022) *Malawian Priest, Sentenced in Albino's Murder, Dies*, *VOA News*. Available at: https://www.voanews.com/a/malawian-priest-sentenced-in-albino-s-murder-dies/6666727.html (Accessed: 25 September 2022).

Mayo Clinic (2022) *Autosomal Recessive Inheritance*, *Mayo Clinic*. Available at: https://www.mayoclinic.org/autosomal-recessive-inheritance-pattern/img-20007457 (Accessed: 12 March 2022).

Mbogoni, L., E.Y. (2013) 'Human Sacrifice and the Killings of Albinos in Tanzania', in *Human Sacrifice and the Supernatural in African History*. Dar es Salaam: Mkuki na Nyota Publishers Ltd, pp. 115–139.

MedlinePlus (2022) *Hermansky-Pudlak Syndrome*. Available at: https://medlineplus.gov/genetics/condition/hermansky-pudlak-syndrome/#references (Accessed: 12 March 2022).

Mis, M. (2015) *Attacks Against Albinos Rise in Africa as Elections Approach*, *Reuters*. Available at: https://www.reuters.com/article/uk-africa-albinism-election-idUKKCN0S923G20151015 (Accessed: 25 September 2022).

Monaghan, J. and Just, P. (2000) *Social and Cultural Anthropology: A Very Short Introduction*. New York: Oxford University Press.

Morelli, J. (2015) *Fotografier av döda*, *SFF*. Available at: https://www.sfoto.se/nyheter/fotografier-av-doda/ (Accessed: 30 August 2022).

Morton, B. (2020) *All Shook Up: The Politics of Cultural Appropriation*. Available at: https://www.dissentmagazine.org/article/all-shook-up-the-politics-of-cultural-appropriation (Accessed: 25 October 2022).

Moyo, A. (2007) 'Religion in Africa', in A. Gordon and D. Gordon (eds) *Understanding Contemporary Africa*. 4th ed. Boulder: Lynne Rienner Publishers, Inc.

Mugeere, A.B. *et al.* (2020) '"Oh God! Why Did You Let Me Have This Disability?": Religion, Spirituality and Disability in Three African countries', *Journal of Disability & Religion*, 24(1), pp. 64–81. Available at: https://doi.org/10.1080/23312521.2019.1698387.

Netema, V. (2008) 'In Hiding for Exposing Tanzania Witchdoctors', *BBC News*, 24 July. Available at: http://news.bbc.co.uk/2/hi/africa/7523796.stm.

New York Times (2018) *Albino Pageant Carries a Serious Message*, *New York Times*. Available at: https://www.nytimes.com/2018/12/01/world/africa/albino-beauty-pageant-nairobi.html (Accessed: 24 September 2022).

NHS (2020) *Albinism*, *NHS*. Available at: https://www.nhs.uk/conditions/albinism/ (Accessed: 12 March 2022).

Nzwili, F. (2022) *Malawi Priest Sentenced to 30 Years for Murder of Man with Albinism*, *UCA News*. Available at: https://www.ucanews.com/news/malawi-priest-sentenced-to-30-years-for-murder-of-man-with-albinism/97849 (Accessed: 25 September 2022).

Obaji, Jr., P. (2022) *'Albino Hunters' Accused of Kidnapping and Butchering Children*, *The Daily Beast*. Available at: https://www.thedailybeast.com/albino-hunters-accused-of-kidnapping-and-butchering-children-in-madagascar (Accessed: 24 September 2022).

Obulutsa, G. (2009) 'Interview - Canadian Group Vows to Fight Tanzania Albino Murders', *Reliefweb*, 12 September. Available at: https://reliefweb.int/report/united-republic-tanzania/interview-canadian-group-vows-fight-tanzania-albino-murders (Accessed: 16 April 2022).

Oestigaard, T. (2014) 'Witchcraft and Witch killings', in *Religion at Work in Globalised Traditions: Rainmaking, Witchcraft and Christianity in Tanzania*. Newcastle: Cambridge Scholars Publisher.

OHCHR (2019) *Malawi: UN Experts Urge Action Over Albinism 'Atrocities' in Run-up to Elections*, *United Nations. Human Rights Office of the High Commissioner*. Available at: https://www.ohchr.org/en/press-releases/2019/02/malawi-un-experts-urge-action-over-albinism-atrocities-run-elections (Accessed: 25 September 2022).

OHCHR (2021) *Witchcraft Killings of People with Albinism Rose During Pandemic – UN Expert*. United Nations, Human Rights Office of the High Commissioner. Available at: https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=27346&LangID =E> (Accessed: 16 September 2021).

Ojilere, A. and Saleh, M.M. (2019) 'Violation of Dignity and Life: Challenges and Prospects for Women and Girls with Albinism in Sub-Saharan Africa', *Journal of Human Rights* *and Social Work*, 4(3), pp. 147–155. Available at: https://doi.org/10.1007/s41134-018-0085-0.

Ongiri, P., Saramba (2015) *19 Face Death Penalty Over Albino Killings in Tanzania*, *AA*. Available at: https://www.aa.com.tr/en/world/19-face-death-penalty-over-albino-killings-in-tanzania/517433 (Accessed: 24 September 202AD).

PAC (2015) *Reported Attacks of Persons with Albinism*, *PAC (Peacemakers for Albinism and Community)*. Available at: https://www.albinism-tz.org/albinism-in-tanzania (Accessed: 16 April 2022).

People With Albinism (2022) *Salif Keita, World Renowned Musician and Activist*, *People With Albinism: Not Ghosts but Human Beings*. Available at: https://albinism.ohchr.org/story-salif-keita.html (Accessed: 24 September 2022).

PEW (2010) *Tolerance and Tension: Islam and Christianity in Sub-Saharan Africa*. Pew Forum on Religion & Public Life.

Ransford-Oppong, J. (2010) 'Culture, Conflict, and Change in Sub-Saharan Africa', in S. Aryeetey-Attoh (ed.) *Geography of sub-Saharan Africa*. 3rd ed. New York: Prentice Hall.

Rao, P. (2018) *Ending Albino Persecution in Africa*, *Equal Times*. Available at: https://www.un.org/africarenewal/magazine/december-2017-march-2018/ending-albino-persecution-africa (Accessed: 31 August 2022).

Ravi, T. (2009) 'Witch Doctors Butcher Tanzania's Albinos for "Lucky Potions"', *MedIndia*, 5 February. Available at: https://www.medindia.net/news/witch-doctors-butcher-tanzanias-albinos-for-lucky-potions-47152-1.htm (Accessed: 16 April 2022).

RFI (2016) *UN Expert Questions 'Witchcraft' as Cause of Rising Albino Violence*, *RFU*.

van Rijn, J., Barham, B. and Sundaram-Stukel, R. (2017) 'An Experimental Approach to Comparing Similarity- and Guilt-Based Charitable Appeals', *Journal of Behavioral and Experimental Economics*, 68, pp. 25–40. Available at: https://doi.org/10.1016/j.socec.2017.02.004.

Román, L. (2021a) 'Albinism, Magic, and Religious Beliefs in Africa. A Minor Critical Discourse Analysis with a Focus on Tanzania.', in.

Román, L. (2021b) 'Lånar du ut din solkräm?', 16 May. Available at: https://www.facebook.com/LinneaRoman/posts/10214717186562557.

Román, L. (2021c) 'The Invisible Human Beings: Persecuted and Killed in the Shadows of the Society', *Linnéa Román*. Available at: https://linnearoman.com/article.

Román, L. (2022) 'Lilla S', 17 January. Available at: https://www.facebook.com/liinnearoman/photos/a.195374286133581/227103096294033/.

Salary Explorer (2022) *Average Salary in Tanzania 2022*, *Salary Explorer*. Available at: https://www.salaryexplorer.com/salary-survey.php?loc=214&loctype=1 (Accessed: 8 July 2022).

Savage, M. (2019) *Meet Lazarus, the Malawian Musician Destroying Myths About Albinism*, *BBC News*. Available at: https://www.bbc.com/news/entertainment-arts-48021425 (Accessed: 24 September 2022).

Schraeder, P. (2004) *African Politics and Society - A Mosaic in Transformation*. 2nd ed. Belmont: Thomson.

Schüle, J. (2013) *Medicine Murder of People with Albinism in Tanzania – How Casino Capitalism Creates Rumorscapes and Occult Economies*. Working Papers. Freie Universität Berlin.

Septianto, F. and Paramita, W. (2021) 'Sad but Smiling? How the Combination of Happy Victim Images and Sad Message Appeals Increase Prosocial Behavior', *Marketing Letters*, 32, pp. 91–110.

SFF (2013) *Fotografera barn - vad gäller?*, *Svenska Fotografers Förbund*. Available at: https://www.sfoto.se/forbundsnytt/fotografera-barn-vad-galler/ (Accessed: 30 August 2022).

SFF (2018) *Hur påverkas du som fotograf av den nya lagen GDPR? (1)*, *Svenska Fotografers Förbund*. Available at: https://www.sfoto.se/juridik/hur-paverkas-du-som-fotograf-av-den-nya-lagen-gdpr/ (Accessed: 30 August 2022).

Shier, M.L. and Handy, F. (2012) 'Understanding Online Donor Behavior: the Role of Donor Characteristics, Perceptions of the Internet, Website and Program, and Influence from Social Networks', *International Journal of Non-profit and Voluntary Sector Marketing*, 17(3), pp. 219–230. Available at: https://doi.org/10.1002/nvsm.1425.

Slovic, P. (2010) 'If I Look at the Mass I Will Never Act: Psychic Numbing and Genocide', in S. Roeser (ed.) *Emotions and Risky Technologies*. Dordrecht: Springer Netherlands (The International Library of Ethics, Law and Technology), pp. 37–59. Available at: https://doi.org/10.1007/978-90-481-8647-1_3.

Slovic, P. *et al.* (2017) 'Iconic Photographs and the Ebb and Flow of Empathic Response to Humanitarian Disasters', *Proceedings of the National Academy of Sciences*, 114(4), pp. 640–644. Available at: https://doi.org/10.1073/pnas.1613977114.

Small, D.A. and Loewenstein, G. (2003) 'Helping a Victim or Helping the Victim: Altruism and Identifiability', *The Journal of Risk and Uncertainty*, 26(1), pp. 5–16.

Small, D.A., Loewenstein, G. and Slovic, P. (2007) 'Sympathy and Callousness: The Impact of Deliberative Thought on Donations to Identifiable and Statistical Victims', *Organizational Behavior and Human Decision Processes*, 102(2), pp. 143–153. Available at: https://doi.org/10.1016/j.obhdp.2006.01.005.

Small, D.A. and Verrochi, N.M. (2009) 'The Face of Need: Facial Emotion Expression on Charity Advertisements', *Journal of Marketing Research*, 46(6), pp. 777–787. Available at: https://doi.org/10.1509/jmkr.46.6.777.

Smith, A.D. (2008) 'Albino Africans Live in Fear After Witch-Doctor Butchery', *The Guardian*, 16 November. Available at: https://www.theguardian.com/world/2008/nov/16/tanzania-humanrights (Accessed: 16 April 2022).

Sontag, S. (2003) *Regarding the Pain of Others*. New York: Picador.

Standing Voice (2015) *Murder and Mutilation*. Available at: https://www.standingvoice.org/albinism (Accessed: 16 April 2022).

Standing Voice (2021) *Reported Human Rights Violations Against People with Albinism in Africa*. Available at: https://twitter.com/StandingVoice/status/1403313552723677184/photo/1 (Accessed: 16 April 2022).

Steen, A. (2019) *Hope for the Hunted: Children Maimed in Unspeakable Crimes Heal on Staten Island*, *Silive*. Available at: https://www.silive.com/news/2019/06/hope-for-the-hunted-children-maimed-in-unspeakable-crimes-heal-on-staten-island.html (Accessed: 17 April 2022).

Tanzania Albino Attacks: 'My Neighbour Hacked Off My Hands' (2017). Available at: https://www.bbc.com/news/av/world-africa-40300824 (Accessed: 31 October 2022).

Tato, L. (2018) *The First Ever Mr and Miss Albinism East Africa*, *Aljazeera*. Available at: https://www.aljazeera.com/gallery/2018/12/26/the-first-ever-mr-and-miss-albinism-east-africa (Accessed: 24 September 2022).

Taylor, A. (2015) 'Albino Children in Tanzania Targeted by Body Part Hunters', *The Atlantic*, 1 October. Available at: https://www.theatlantic.com/photo/2015/10/albino-children-in-tanzania-targeted-by-body-part-hunters/408469/ (Accessed: 16 April 2022).

Taylor, J. *et al.* (2021) ‘Reactions to and Explanations for the Birth of a Baby with Albinism: A Qualitative Study in Busoga, Uganda’, *BMJ Open*, 11(2), p. e040992. Available at: https://doi.org/10.1136/bmjopen-2020-040992.

The Citizen (2022) *Malawi Catholic Priest Jailed for 30 Years over Albino Murder*, *The Citizen*. Available at: https://www.thecitizen.co.tz/tanzania/news/africa/malawi-catholic-priest-jailed-for-30-years-over-albino-murder-3861492 (Accessed: 25 September 2022).

The Danger of Living with Albinism in a Highly Superstitious Society (2020). Capital FM. Available at: https://www.youtube.com/watch?v=XvfVhwKn_Tw.

The Hunted Children of Tanzania: Mutilated for Profit (2019). Available at: https://www.youtube.com/watch?v=b7eVB6O1Kaw&t=120s (Accessed: 18 May 2022).

The University of Arizona Health Sciences (2022) *Albinism, Oculocutaneous, Type I*, *The University of Arizona Health Sciences: Hereditary Ocular Disease*. Available at: https://disorders.eyes.arizona.edu/disorders/albinism-oculocutaneous-type-i (Accessed: 25 September 2022).

UN (2013) *Persons with Albinism: Report of the Office of the United Nations High Commissioner for Human Rights**. Annual Report A/HRC/24/57. Available at: https://www.google.com/url?sa=t&rct=j&q=&esrc=s&source=web&cd=&ved=2ahUKEwiJwfnLt6_6AhXvQkEAHTOZBxAQFnoECAcQAQ&url=https%3A%2F%2Fwww.ohchr.org%2Fsites%2Fdefault%2Ffiles%2FHRBodies%2FHRC%2FRegularSessions%2FSession24%2FDocuments%2FA_HRC_24_57_ENG.doc&usg=AOvVaw1kfnsBlT1Bb_daHvo36q71.

UN Geneva (2022) *In the Shadow of the Sun*, *UN Geneva*. Available at: https://www.ungeneva.org/en/events/2022/06/shadow-sun (Accessed: 28 October 2022).

Uppsala University (2022) *CODEX Rules and Guidelines for Research*, *Uppsala University*. Available at: https://codex.uu.se/?languageId=1 (Accessed: 29 August 2022).

UTSS (Under the Same Sun) (2012) ‘Frequency of Albinism/Rates of Occurrence’. Available at: https://www.underthesamesun.com/sites/default/files/Frequency%20of%20Albinism.pdf (Accessed: 6 February 2022).

Wallace, D. (2015) ‘Rethinking Religion, Magic and Witchcraft in South Africa: From Colonial Coherence to Postcolonial Conundrum’, p. 29.

Wesangula, D. (2015) ‘Albinism in Tanzania: Slow Progress in Combatting Violence and Discrimination’, *The Guardian*, 13 May. Available at: https://www.theguardian.com/global-development-professionals-network/2015/may/13/albinism-in-tanzania-slow-progress-in-combatting-violence-and-discrimination (Accessed: 17 April 2022).

Wessel, J. (2018) *GDPR: Så påverkas fotografer av den nya lagen*, *Kamera & Bild*. Available at: https://www.kamerabild.se/nyheter/lag-upphovsr-tt/gdpr-s-p-verkas-fotografer-av-den-nya-lagen (Accessed: 30 August 2022).

Whowns Kenya (2022) *Martin Wanyonyi: The First Person with Albinism To Be Elected MP In Kenya*, *Whowns Kenya*. Available at: https://whownskenya.com/index.php/2022/08/22/martin-wanyonyi-the-first-person-with-albinism-to-be-elected-mp-in-kenya/ (Accessed: 24 September 2022).

Wolford, B. (2022) *What is GDPR, the EU’s New Data Protection Law?*, *GDPR.EU*. Available at: https://gdpr.eu/what-is-gdpr/ (Accessed: 29 August 2022).

World Population Review (2022) *World Population Review*. Available at: https://worldpopulationreview.com/countries/tanzania-population (Accessed: 5 August 2022).

Wright, K. (2018a) '"Good" Journalism and Moral Economies', in *Who's Reporting Africa Now? Non-Governmental Organizations, Journalists and Multimedia*. New York: Peter Lang, pp. 63–93.

Wright, K. (2018b) 'Introduction', in *Who's Reporting Africa Now? Non-Governmental Organizations, Journalists and Multimedia*. New York: Peter Lang, pp. 1–35.

Wright, K. (2018c) 'Photojournalism, Professionalism, and Print Newspapers', in *Who's Reporting Africa Now? Non-Governmental Organizations, Journalists and Multimedia*. New York: Peter Lang, pp. 63–93.

Wullfhorst, E. (2015) *Tanzanian Albino Children Attacked for Body Parts Face Return Home From USA*, *Reuters*. Available at: https://www.reuters.com/article/us-usa-tanzania-albinism-idUSKCN0RU2V320150930 (Accessed: 17 April 2022).

Yeboah, I., E.A. (2010) 'Historical Geography of Sub-Saharan Africa: Opportunities and Constraints', in S. Aryeetey-Attoh (ed.) *Geography of sub-Saharan Africa*. 3rd ed. New York: Prentice Hall.

York, G. (2010) 'Hunted for Body Parts, Tanzania's Albinos Get Help from B.C. Man', *The Globe and Mail*, 26 April. Available at: https://www.theglobeandmail.com/news/world/hunted-for-body-parts-tanzanias-albinos-get-help-from-bc-man/article1314187/ (Accessed: 16 April 2022).

Zarzycka, M. (2015) 'Save the Child: Photographed Faces and Affective Transactions in NGO Child Sponsoring Programs', *European Journal of Women's Studies*, 23(1), pp. 28–42. Available at: https://doi.org/10.1177/1350506814568362.

Appendix A

Table A1. A summarised table of the ways I have engaged the public about albinism and the responses they led to.

<table>
<tr><th colspan="10">WAYS I HAVE TALKED ABOUT ALBINISM:</th></tr>
<tr><td colspan="2">(1) INSTAGRAM STORIES</td><td colspan="2">(2) INSTAGRAM POSTS</td><td colspan="2">(3) FACEBOOK POSTS</td><td></td><td>(4) PHOTO EXHIBITION</td><td>(6) LECTURES</td><td>(7) WEBINAR</td></tr>
<tr><td>About Albinism:</td><td>111</td><td colspan="2" rowspan="5">Narrated stories from the field:

19</td><td colspan="2" rowspan="5">Narrated stories from the field:

27</td><td rowspan="5"></td><td rowspan="5">10 photos</td><td rowspan="5"></td><td rowspan="5">Screening of the documentary and conversation with Sr. Martha</td></tr>
<tr><td>First Fundraising:</td><td>32</td></tr>
<tr><td>Second Fundraising:</td><td>5</td></tr>
<tr><td>Third Fundraising:</td><td>32</td></tr>
<tr><td>Awareness Products</td><td></td></tr>
<tr><th colspan="10">PUBLIC RESPONSES:</th></tr>
<tr><td colspan="6">(A) SOCIAL MEDIA INTERACTIONS:</td><td rowspan="4"></td><td colspan="3">(B) PARTICIPATING</td></tr>
<tr><td>Quiz:</td><td>482</td><td>Likes:</td><td>680</td><td>Likes:</td><td>686</td><td rowspan="3">35</td><td rowspan="3">≈ 40</td><td rowspan="3">24</td></tr>
<tr><td>Slider:</td><td>117</td><td rowspan="2">Comments:</td><td rowspan="2">45</td><td>Comments:</td><td>172</td></tr>
<tr><td>Poll:</td><td>208</td><td>Shares:</td><td>46</td></tr>
<tr><td colspan="10">(C) DONOR GIVING</td></tr>
<tr><td colspan="5"></td><td colspan="3">Number of donors</td><td colspan="2">Amount raised (SEK)</td></tr>
<tr><td colspan="5">First Fundraising (May 2021)</td><td colspan="3">47</td><td colspan="2">13,691</td></tr>
<tr><td colspan="5">Second Fundraising (December 2021)</td><td colspan="3">8</td><td colspan="2">3,900</td></tr>
<tr><td colspan="5">Third Fundraising (June 2022)</td><td colspan="3">22</td><td colspan="2">10,230</td></tr>
<tr><td colspan="5">Giving in between fundraising campaigns</td><td colspan="3">7</td><td colspan="2">4,300</td></tr>
<tr><td colspan="5">Total</td><td colspan="3">84</td><td colspan="2">32,121</td></tr>
<tr><td colspan="10">(D) BUYING ALBINISM AWARENESS PRODUCT</td></tr>
<tr><td colspan="5"></td><td colspan="3">Units sold</td><td colspan="2">Profit (SEK) to donate</td></tr>
<tr><td colspan="5">Tote Bags</td><td colspan="3">117</td><td colspan="2">7,487*</td></tr>
<tr><td colspan="5">Makeup Bags and Coin Purses</td><td colspan="3">27</td><td colspan="2">1,272*</td></tr>
<tr><td colspan="5">Certificate of Donation – Christmas Gifts</td><td colspan="3">21</td><td colspan="2">4,005</td></tr>
<tr><td colspan="5">Total</td><td colspan="3">165</td><td colspan="2">12,764</td></tr>
</table>

*Profit from 2022 is not included.

Appendix B

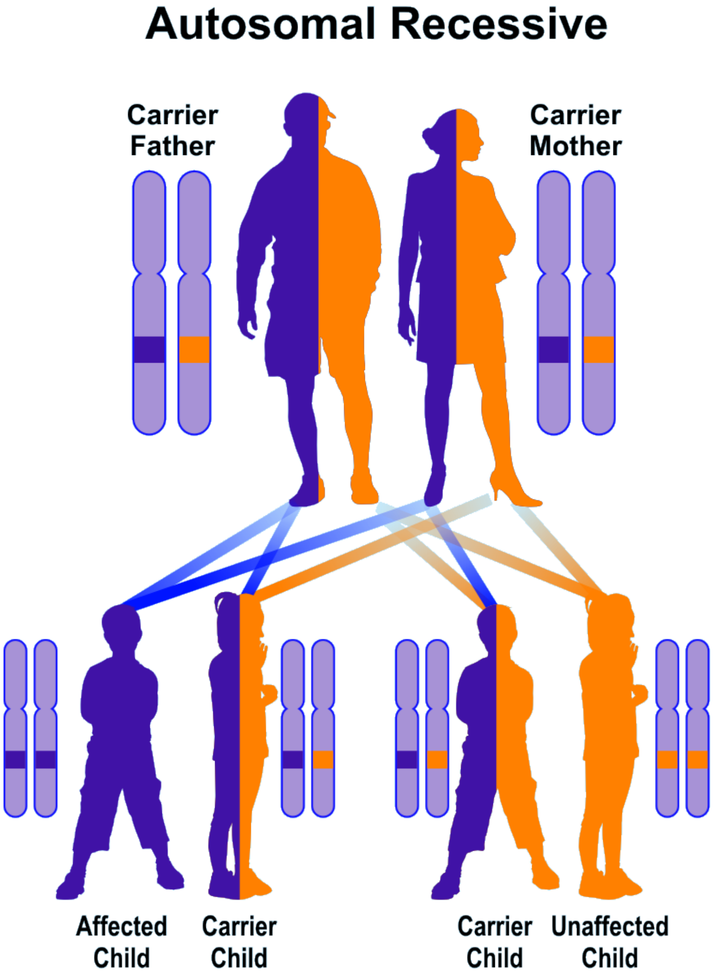

Figure B1. Autosomal recessive inheritance. Reprinted from The Univeristy of Arizona Health Sciences (2022). Retrieved from: https://disorders.eyes.arizona.edu/disorders/albinism-oculocutaneous-type-i

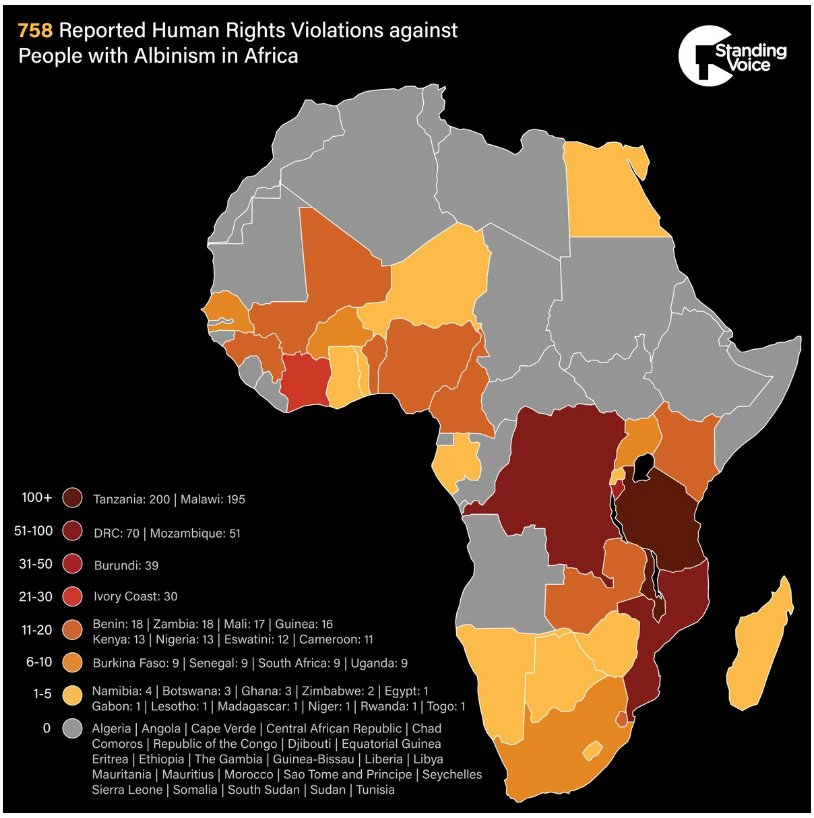

Figure B2. Map of Reported Human Rights Violations against People with Albinism in Africa. Reprinted from the Standing Voice (2021). Retrieved from: https://twitter.com/standingvoice/status/1403313552723677184

Figure B3. The Terror of War. Reprinted from Huynh Cong "Nick" Ut., 1972. AP (The Associated Press). Retrieved from: https://aboutphotography.blog/blog/the-terror-of-war-nick-uts-napalm-girl-1972

Figure B4. The Vulture and the Little Girl. Reprinted from Kevin Carter., 1993. New York Times. Retrieved from: https://talkafricana.com/the-struggling-girl-the-story-behind-one-of-the-most-recognizable-pictures-of-all-time/

Figure B5. Alan Kurdi. Reprinted from Nilüfer Demir, 2015., Doğan News Agency. Retrieved from: https://www.aljazeera.com/news/2016/9/2/alan-kurdi-what-has-changed-since-his-death

Appendix C

Figure C1. Small S. Reprinted from Linnéa Román., 2021. Retrieved from: https://www.facebook.com/photo/?fbid=227103096294033&set=pb.100076038513225.-2207520000.

Figure C2. School Boys with Albinism. Reprinted from Linnéa Román., 2021. Retrieved from: https://www.instagram.com/p/CQoByWHHdln

Figure C3. Portrait of Girl with Albinism. Reprinted from Linnéa Román., 2021. Retrieved from: https://www.facebook.com/liinnearoman/photos/pb.100076038513225.-2207520000./221921450145531/?type=3