EXPLORING THE EXPERIENCE OF MOTHERS WHO HAVE CHILDREN WITH

ALBINISM IN TANZANIA: A CRITICAL ETHNOGRAPHY

by

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Abstract

Little is understood about the everyday lives of mothers of children with albinism in sub-Saharan Africa, specifically Tanzania. This region has a harrowing history of discrimination and violent attacks against persons with albinism, largely rooted in cultural/spiritual beliefs and practices, and perpetuated by layers of myth about albinism. A focused critical ethnographic study, through the lens of Hudson-Weems' (2019) Africana Womanism, explored the experiences of mothers of children with albinism in Tanzania, addressed the gendered nature of this condition, and considered the human rights and resilience of the mothers. One participant's story illuminated human rights and resilience from a mother's standpoint, which was the backdrop for the presentation of findings that included stories of other mothers with albinism and the perspectives of key stakeholders. These findings highlight the social ecological nature of resilience for these mothers. Recommendations focus on policy, advocacy, and research related to health and social services and education.

Acknowledgements

This has been a humbling journey. Sitting face-to-face with women impacted by albinism boldly declaring their stories—the grief, the triumph, the anger, the hope, the *knowing*—changed my idea of the role academic research can play in the broader story of humanity. This study does not exist because of me and my work: It exists because of the women impacted by albinism who, desiring to see change at all levels, agreed to share their experiences with me. This research is dedicated to these women: May this work be part of the loudspeaker amplifying your powerful voices.

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Without the constant love, support, and encouragement from my family I would never have started this journey. Mom, Dad, Lela, thank you for believing in me and cheering me on always: I love you. Throughout this work, I have reflected on the journeys of the women in my

family that paved the way. My late grandmother, Mary Emma Hill Strobell, who as a geologist for the USGS in the 1950s to 70s broke several glass ceilings in her own profession. Grandma, thank you for instilling in me a deep curiosity about the world, a sense that I could achieve anything I set my mind and heart to, and to not fear different ideas or belief systems but to see the humanity inside of everyone. And my late Mima, D'Metra Maddox, your tenacity, feisty spirit, and perseverance in the face of hardship reminds me to keep going, to keep challenging myself, and to acknowledge the many unearned privileges that I walk in. I am proud to identify with these strong women and to carry their spirits with me.

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Chapter One: Introduction and Background

In recent years, media coverage, policy documents, and academic literature have exposed the troubling levels of stigma, discrimination, threats to physical and emotional security, as well as various threats to health faced by persons with albinism, with most of these reports focused on sub-Saharan Africa (Reimer-Kirkham, Astle, Ero, Panchuk, & Dixon, 2019; United Nations General Assembly [UNGA], 2016a). Many of the stigmas and discrimination experienced by persons with albinism in areas of Africa are related to various spiritual and/or cultural beliefs and practices that are rooted in layers of myth and mystery drawing on African ontology (Baker, Lund, Nyathi, & Taylor, 2010; Imafidon, 2017; Reimer-Kirkham et al., 2019). Such beliefs can deem persons with albinism as super or subhuman. In conjunction, a gap exists in culturally relevant knowledge dissemination regarding the genetic causes of the condition (Baker et al., 2010). Even though the genetics of the disease are such that both parents are recessive carriers, many of the spiritual/cultural beliefs about the causes of albinism are gendered (e.g., conception during menstruation, affair with a white man), such that mothers are disproportionately blamed and otherwise put at risk for additional harm (e.g., sexual violence) on account of these beliefs (Brocco, 2016; Franklin, Lund, Bradbury-Jones, & Taylor, 2018; Reimer-Kirkham et al., 2019). Recent media coverage concerning mutilation, killings, and trafficking of body parts of persons with albinism for charms and profit in Tanzania, particularly where it concerns affected children, have brought such stories to an international level (Brocco, 2015; Human Rights Watch, 2017; Ntetema, 2008; Reimer-Kirkham et al., 2019).

Of particular concern is the lack of research related specifically to the experiences of women and girls affected by albinism: both mothers of children with albinism as well as women

and girls with albinism themselves (UNGA, 2019a). Research on the experiences of persons with albinism in Africa has gained ground since the mid-2000s, adding to the existing literature on albinism as a genetic condition (Estrada-Hernandez & Harper, 2007; Reimer-Kirkham et al., 2019). However, little of this has focused specifically on mothering. And yet, because of the gendered nature of beliefs about albinism, the level of stigma and violence faced by persons with albinism, and the critical role of mothers in protecting their children with albinism, understanding the experiences of mothers impacted is of paramount importance. Thus, the aim of my research is to explore such experiences. I was invited by the UN Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, and *NGO-1* (to ensure confidentiality, the NGO will not be identified by name) to conduct this research. I connected with women who have children with albinism who access programs of two different NGOs in Dar es Salaam and Mwanza, Tanzania. My hope was that through conducting critical ethnographic research, women impacted can add their experiences of mothering children with albinism to the literature in an effort to further the protection and promotion of the human rights of persons with albinism and provide necessary information related to resources, policy, and advocacy that can extend beyond the Tanzanian context.

Throughout my undergraduate studies and well into my career as a community health nurse in Northern Canada, my passion for human rights, particularly as experienced by women and girls on a global scale, has endured. My interest in pursuing this passion as an area of study began in 2017 when I joined a broader Social Sciences Health Research of Canada-funded (SSHRC) study on the implications of spiritual/cultural practices on the enjoyment of human rights by persons with albinism as a research assistant. This study aimed to collaboratively set a

research agenda to address the gross human rights violations that persons with albinism

experience in their daily lives in places like Tanzania (Reimer-Kirkham et al., 2019). By the time

I commenced fieldwork for this thesis, our team secured additional funding to further explore the

experiences of mothers impacted by albinism (including mothers with albinism themselves). As

a result, this current study (my thesis) became the pilot project in Tanzania, which is being

followed with additional fieldwork in Tanzania, South Africa, and Ghana. By exploring the

specific experience of women affected by albinism, the findings from this study may assist

policy-makers, advocates, and activists to be better positioned to respond appropriately and

effectively to their hardship.

Background

In the following section, I describe how key concepts of this research coalesce,

highlighting the intersectional nature of albinism within the Tanzanian context: albinism; human

rights and albinism; and mothering and albinism.

Albinism

Oculocutaneous Albinism (OCA) is a genetic condition that causes hypopigmentation of

the skin, eyes, and hair due to an impairment in the synthesis and transport of melanin by

melanocytes (Cruz-Inigo, Ladizinski, & Sethi, 2011). While there are two main types of

albinism, OCA Types 1–7 and Ocular Albinism, OCA Type 2 (OCA 2) is most prevalent in Sub-

Saharan Africa (Kamaraj & Purohit, 2014; Lund, 2001, 2005). There are other rarer forms of

albinism including Hermansky Pudlak Syndrome (HPS) and Chediak Higashi Syndrome. Both of

these rare forms have associated severe systemic problems. OCA 2 is most common in Africa

and represents about 20–30 % of all albinism cases (Kamaraj & Purohit, 2014). Persons with

OCA 2 have pale, white skin, light hair, and light brown or blue eyes which stand in stark contrast to the darker features and melanated skin that is "normal" in sub-Saharan Africa (Lund 2001, p. 1). OCA 2 is a recessive X-linked genetic condition (Kamaraj & Purohit, 2014), in which *both* parents must carry "one mutant (non-working) form of the gene for OCA 2" in order to conceive a child with albinism (Lund, 2001, p. 1). Carrier parents, who most often do not have OCA 2 themselves, have a 1:4 chance per pregnancy of conceiving a child with albinism (Lund, 2001). Children born with OCA 2 have two mutant copies of the gene and are, therefore, unable to produce pigment (a result of melanin) (Lund, 2001).

Melanin, which gives skin its colour, also protects the skin from harmful effects caused by the sun's ultraviolet radiation. Thus people with OCA 2 are at high risk for severe forms of skin cancer, particularly in the sub-Saharan African climate (Cruz-Inigo et al., 2011). Visual impairments, including nystagmus (involuntary movement of the eyes), poor visual acuity, and photophobia affect people with OCA 2, often to an acute degree (Cruz-Inigo et al., 2011). While people from all over the world are affected by OCA, parts of sub-Saharan Africa experience a much higher prevalence, with estimates in Tanzania of 1:1,429 (Cruz-Inigo et al., 2011) versus the estimated 1:20,000 in most populations globally or 1:37,000 in the United States of America (Cruz-Inigo et al., 2011; Lund, 2001). In addition to these health concerns, persons with albinism experience stigma, discrimination, and threats to their physical safety (Brilliant, 2015; Lund, 2001; Reimer-Kirkham et al., 2019). Such threats are based on their skin colour, visual impairment, and various spiritual/cultural beliefs and practices related to the causes of the condition itself that result in social isolation and lack of access to health and social services

(including simple preventative measures such as sunscreen and skin cancer screening) (Reimer-Kirkham et al., 2019).

Human Rights and Albinism

NGOs have been working locally and globally alongside persons with albinism to promote their inclusion within society and ensure access to key resources. These include: Under the Same Sun (UTSS), Standing Voice (SV), and Tanzanian Albinism Society (TAS) in Tanzania; Association for Persons with Albinism–Malawi (APAM); Albinism Society of South Africa (ASSA); and National Organization for Albinism and Hypopigmentation (NOAH), predominately in North America. Other international organizations, such as the United Nations (UN) and the World Health Organization (WHO), however, have been slower to initiate unified and formalized responses related to the concerns faced by persons with albinism. More recently, in 2015, the UN appointed Ikponwosa Ero, herself a person with albinism, as the first UN Independent Expert on the enjoyment of human rights by persons with albinism. While not regularly discussed in academic discourse as "human rights violations," Ero's appointment to such a post and the mandate that falls under her portfolio have certainly elevated the cause of persons with albinism to such a level (Reimer-Kirkham et al., 2019; UNGA, 2016a). There continue, however, to be harrowing reports of persons with albinism who are being murdered or mutilated for their body parts. While there is much to be addressed on this important human rights concern, for the purpose of this study, the focus remained on mothers of children with albinism and their experiences of navigating this in terms of their own experiences as well as how having a child with albinism impacted their parenting/child-rearing.

Increasingly tied to human rights discourse are the UN's Sustainable Development Goals (SDGs). In 2015, the UN introduced these global goals espousing the importance that all persons be acknowledged, building upon the framework of the Millennium Development Goals (MDGs), which focused on more specific populations (UN, 2015). The SDGs are broader in their scope, addressing social, economic, and environmental dimensions. Also embedded within the SDGs is the "pledge that no one will be left behind" (p. 5). The framework of the SDGs has been utilized by Ero in her mandate along with the principle of leaving no one behind serving as a key cornerstone:

> The measures can also be implemented by integrating them into several existing, broader national frameworks, including action plans on human rights, policies on the rights of persons with disabilities and frameworks to combat racial discrimination, on access to health, on the rights of women and children and on access to justice services and victim support services. It is important to ensure, however, that the measures integrated in broader frameworks explicitly address the specificities of the challenges faced by persons with albinism. It is very important that the issue does not become "lost" among others, as the ignorance of the specificities of the rights and needs of persons with albinism has permitted the development of myths that in turn have contributed to the attacks. Indeed, the 2030 Agenda for Sustainable Development alludes to beginning all efforts with those who have been left furthest behind. (UNGA, 2017a, para 99)

While the SDGs provide a broadened scope, when compared to the MDGs, number 5 explicitly addresses the goal to "achieve gender equality and empower all women and girls" (UN, 2015, p. 18). This goal directly reflects this rights-based principle of ensuring no one is left behind

(WHO, 2017). As a result, the focus of this study supports and provides the impetuous for the study of gender implications for mothers of children with albinism and their experiences.

Mothering and Albinism

Women and girls remain particularly vulnerable to human rights violations as a result of the social constructs of gender that continue to enable multiple and intersecting forms of stigma, discrimination, violence, and inequity (Hagues, 2017; UNGA, 2013, 2016a, 2019a). A disability like albinism adds yet another layer to the intersecting structural vulnerabilities that many African women already navigate (Hagues, 2017; Neille & Penn, 2017). As a result, gendered narratives persist within African mythologies and beliefs, and women and girls with albinism are at increased risk of experiencing gender-based violence and sexual assault (Adeyanju, Dipo, & Tayie, 2015; Baker et al., 2010). To this point, Baker et al. (2010) quote a man with albinism in Zimbabwe:

> To be an albino is a terrible thing, but to be a girl albino is the worst of all. You know that the AIDS pandemic, they say the cure is to sleep with a virgin, but if you sleep with a virgin who is albino then even better. There are many rapes… (p. 176)

Neille and Penn (2017) highlighted the intersectionality between disability, violence, and poverty, and affirmed the postulation that women and girls with a disability like albinism are at increased risk for such violence, asserting that "women with disabilities are doubly exposed to sexual violence as a result of gender inequality as well as by nature of their disability" (p. 2854). In their study addressing the social determinants of health (SDoH) and inequity in Tanzania, Mtenga, Masanja, and Mamdani (2016) emphasized that gender inequities persist "because of differences in access to and control over resources in decision-making powers, as well as the

roles and responsibilities that society assigns to them" (p. 2). Hagues (2017) highlighted "a

'triple heritage' " that continues to privilege the treatment of men within sub-Saharan Africa that

includes the intersection between Western/Christian colonial ideologies, Islamic ideologies, and

practices already embedded within traditional African beliefs (p. 110). Exploration into how such

social constructs of gender in a given cultural context further marginalize women and girls with

albinism, as well as mothers of children with albinism is needed to ensure effective strategies in

the protection and promotion of their human rights.

In terms of roles and responsibilities historically held by women within a Tanzanian

context, marriage and family, particularly in rural areas, are key to a woman's social acceptance,

support, and welfare (Franklin et al., 2018; Hagues, 2017). As a result of the myths and spiritual

beliefs surrounding the condition, both women with albinism and mothers of children with

albinism may struggle to find/keep both a partner and a partner's family who are accepting of her

(Franklin et al., 2018). As explored by Brocco (2015), the most important aspect of a woman's

dowry (regardless of whether she herself is a person with albinism) in Tanzania is that she

provides her husband and his family with "healthy (and black) children" (p. 1148). Women who

deliver babies with albinism are believed to be cursed or to have committed a misdeed (e.g.,

infidelity, conception during menstruation, touching a person with albinism while pregnant) and

thus bear the blame for their child having the condition (Adeyanju et al., 2015; Baker et al.,

2010; Brocco, 2015; Cruz-Inigo et al., 2011). These women, subsequently, often face rejection

by their partners, their partners' families, and their communities, exposing women and their

children with albinism to the effects of ostracism and poverty (Franklin et al., 2018; UNGA,

2016a, 2016b, 2019a). The subsequent intersecting drivers of inequities affecting the well-being

of women and their children with albinism are holistic, including access to safety, shelter,
education, healthcare services, food security, economic security, and a sense of belonging within
a broader community. As an example, Franklin et al. (2018) highlighted the very real safety
concerns of children with albinism walking alone as a barrier to accessing education and other
services. Families expressed the necessity of escorting their children with albinism to prevent
violent (physical and psychological) attacks (Franklin et al., 2018). Understanding the added
challenges of managing such safety measures as a single mother of a child with albinism is key
in terms of addressing the gendered nature of mothering a child with a disability like albinism.

The combination of these aforementioned factors and the lack of research related
specifically to the experience of mothers of children with albinism highlights the need for further
rigorous study. This is affirmed by Franklin et al.'s (2018) recent study that called for further
"research into understanding the lives of persons with albinism, especially from their perspective
and within a social-relational model of disability" (p. 7). This study addresses this gap by
examining the mothering experience of mothers of children with albinism in Tanzania, using
Hudson-Weems' (2019) framework of Africana Womanism.

Significance of Findings and Implications for Nursing

Madison (2005) contends "that *critical* ethnography is always a meeting of multiple sides
in an encounter with and among the Other(s), one in which there is negotiation and dialogue
toward substantial and viable meanings that make a difference in the Other's world" (p. 9). This
focused critical ethnographic study continued, in some places, and started, in others, the
conversation regarding the lived experience of mothers of children with albinism within a
gendered and at times violent context in which they must confront regular concerns regarding the

safety, security, and long-term societal inclusion of their children with albinism. The mothers' voices that this study centres on are the very voices with the personal knowledge, experience, and perspectives necessary to further ground the conversation regarding the enjoyment of human rights by persons with albinism, aligning with Ero's UN mandate.

As this study is embedded within the broader project on mothering and albinism, knowledge exchange has been facilitated through existing routes of communication with our partners in the field as well as key stakeholders to whom we are connected by proxy (Reimer-Kirkham et al., 2019). Knowledge exchange incites a non-linear (Davies, Powell, & Nutley, 2016) mutual sharing and learning that acknowledges insights and wisdom on both sides—researcher and researched—exploring methods and approaches to disseminating research findings to various outlets for maximum impact. Davies et al. (2016) suggest that knowledge exchange, as opposed to terminology such as "knowledge translation" or "knowledge mobilization," "embod[ies] greater acknowledgement of non-linearity, multi-way knowledge interaction, and system complexity" (p. 280). This approach to mobilizing research findings fits well within our broader project comprised of multi-sectoral, multi-disciplinary partnerships, allowing for a fluidity of knowledge exchange and enactment.

This study adds several elements to existing literature, namely the themes of: parenting concerns and strategies; the intersectional influences on the experience of mothering children with albinism; access to health and social services as well as health-related knowledge; and how threats to human rights in their everyday lives influence their health and well-being. During a time in history where the threats to the human rights of persons with albinism have gained international attention, particularly in sub-Saharan Africa, this study is timely.

As global leaders in healthcare, nurses must continue to position themselves within the human rights agenda—regardless of context or location. Not only does the Canadian Nurses Association (CNA) (2017) Code of Ethics provide sufficient support for such global health involvement, the International Council of Nurses (ICN) (2011) explicitly supports the UN Declaration of Human Rights and states that "nurses have an obligation to safeguard, respect and actively promote people's health rights at all times and in all places" (p. 2). Further, the ICN (2018) theme for the year 2018 was "Nurses: A Voice to Lead—Health is a Human Right" (para. 1). By elucidating the lived experience of mothers of children with albinism, this study can equip nurses at local, national, and international levels to promote access to health and social services, health-related knowledge, and the protection and enjoyment of the human rights of persons with albinism via policy, frontline practice, education and research.

Definition of Terms

This section clarifies the terms used to explore the experiences of mothers impacted by albinism throughout this study. These terms include "albinism," "mothering," "health," "human rights," and "social constructions of gender."

Albinism

Throughout this study, albinism refers to Oculocutaneous Albinism (OCA), which is a recessive genetic condition in which the synthesis and transport of melanin by melanocytes is affected, resulting in hypopigmentation of the skin, eyes, and hair (Cruz-Inigo et al., 2011). People with OCA are at increased risk for severe forms of skin cancer as well as vision impairment, photophobia, and nystagmus (involuntary movement of the eyes) (Cruz-Inigo et al., 2011; Lund, 2001). Beyond the physical implications of this genetic condition, this study

acknowledges the human rights violations experienced by persons with this condition due to
inaccurate beliefs regarding its cause (Reimer-Kirkham et al., 2019).

Mothering

Mothering includes both biological mothers of children with albinism as well as women
who are primary caregivers of children with albinism (Oxford English Dictionary, 2018). It is
recognized that "collective child-rearing" is common within African contexts, where
grandmothers, other female relatives, and older siblings are also involved in child-rearing
(Muthuzkrishna & Ebrahim, 2014, p. 370).

Health

The definition of health for this study aligns with the WHO's (2006) constitution which
states the following:

> Health is a state of complete physical, mental and social well-being and not
>
> merely the absence of disease or infirmity. The enjoyment of the highest attainable
>
> standard of health is one of the fundamental rights of every human being without
>
> distinction of race, religion, political belief, economic or social condition. (para. 1)

Human Rights

Human rights, as defined by the United Nations (2020), are the intrinsic rights of every
human regardless of "nationality, place of residence, sex, national or ethnic origin, colour,
religion, language, or any other status" (para. 1). Human rights ensure the "right to life, liberty,
and security of person" (United Nations, 1948, p. 2). This study acknowledges that the threats to
security, health, and well-being of persons with albinism are direct violations of their human
rights as defined under international law.

Social Constructions of Gender

Gender is explored as an experience embedded within social, political, economic, and cultural discourses—a construct that has direct implications on one's security, health, position in society, and access to resources (Lorber, 1991). Lorber (1991) described gender as "constantly created and re-created out of human interaction, out of social life, and is the texture and order of that social life" (p. 112). Gender affects expectations of mothers versus fathers in terms of parenting, and, as specifically explored by Muthukrishna and Ebrahim (2014), mothering is socially constructed in that "discourses create expectancies about relationships, and influence thoughts and behaviours that shape the nature of the interactions" (p. 370). Further, it has been noted that girls with albinism experience increased human rights violations, particularly in terms of safety, security, and education (Franklin, et al., 2018).

<center>**Purpose and Research Objectives**</center>

The purpose of this focused critical ethnographic study was to explore the social influences on the experience of mothering children with albinism in Tanzania. The objectives were:

1. To describe the primary concerns and parenting strategies employed by mothers in their day-to-day care of children with albinism in Tanzania.

2. To examine how mothers and their children in this particular context access health and social services, including health-related knowledge.

3. To analyze how threats to human rights in their everyday lives (e.g., stigma, discrimination, violence) influence their mothering and health.

4.   To explore the influencing factors of social support, poverty, and sociocultural views on

the experience of mothering in this context.

Research Method

As noted above, this ethnographic study is embedded within a broader, four-year study

on mothering and albinism in Tanzania, South Africa, and Ghana. I collected data in Tanzania

over two fieldwork visits, an initial six weeks (March–May 2019) followed by a four-week

(October–November 2019) trip six months later. Within this time frame, I interviewed a total of

62 participants alongside a cultural liaison, J. Waithera. We interviewed 26 mothers (both

women who have children with albinism and mothers with albinism themselves) and 36 key

informants. My thesis draws on the entirety of my time in the field while focusing specifically on

mothers with children with albinism and a smaller sample size for analysis. Data was collected

employing methods of critical ethnography (Carspecken, 1996; Madison, 2015), including

extensive reflective fieldnotes; participant observation; semi-structured interviews, both one-on-

one and in sharing circles; and extensive debrief conversations with the cultural liaison, local

research partners, and my thesis supervisory committee members, Drs. Reimer-Kirkham and

Astle. All interviews were audio-recorded and transcribed. I used QSR International's NVivo^{TM}

12 software to support data analysis. Throughout the research process and reflected within this

thesis, I sought to remain cognizant of and acknowledge my own positionality as researcher (i.e.,

outsider, white, North American, privileged) in my approach to this method. However, blind

spots remained and hindsight is undoubtedly 20/20 (Simandan, 2019).

Outline of Thesis

This thesis is organized into seven chapters. In Chapter One, I introduced the relevance and timeliness of including the gendered nature of albinism more specifically into current scholarship. I presented the definitions, purpose, objectives, and research methods that guided the study. Chapter Two provides a review of related scholarly literature that supports the aim of this research and underscores the necessity for this study. The research methods are presented in Chapter Three and include sampling strategies, data collection, data analysis, considerations for scientific rigour, ethical considerations for conducting international research, and limitations. Chapters Four and Five, collectively, present the research findings. Chapter Four presents a narrative case study of one of the mothers that embodies a number of key experiences affirmed by several other mothers in this study. Her story is followed by a reflexive section from my position as researcher. Drawing from this case study, Chapter Five weaves together the key storylines and subplots that serve to illustrate the experiences of mothers who have children with albinism in Tanzania. Drawing on the theoretical lens of Hudson-Weems' (2019) Africana Womanism, deeper analysis of the data was conducted. Chapter Six presents a discussion of key study findings, focusing on resilience and human rights through the lens of Hudson–Weems' (2019) Africana Womanism. Finally, Chapter Seven concludes the study, presenting recommendations for engaging the voices of mothers impacted by albinism to improve the lives of women and their children affected. Recommendations are offered for policy, NGOs/CSOs, health and social services, education, research, and leadership.

Figure 1. Approaching a ferry terminal in Mwanza, Tanzania, en route to another fieldwork site.

Chapter Two: Literature Review

This chapter outlines the review of current literature related to mothering in the context of albinism. I will begin by detailing my search strategy, including search terms, databases, forward/backward citation searches, inclusion/exclusion criteria, and extraction questions used to obtain relevant data. Based on research objectives, I will discuss areas that the research literature addresses related to the experience of mothering, broad support provided to mothers, access to health and social services, influences on the experience of mothering children with albinism, and, lastly, threats to human rights and health as experienced by women and their children.

Search and Retrieval Strategies for Literature Review

In consultation with a research librarian, I developed a search strategy for the following databases: Library One Search, CINAHL, CINAHL Subject Headings, MEDLINE, PsycInfo, PsycInfo Thesaurus, Academic Search Complete, Academic Search Complete, Subject Headings, and EMBASE. Based on the purpose and research objectives outlined above, several keywords relevant to the themes were identified and joined using Boolean AND or OR strings (see Appendix A: Literature Review Search Strategy): "Africa* OR Tanzania* OR Malawi* OR Zimbabw* OR Sub-Sahara*"; "child* OR infant OR baby OR babies OR adolescen* OR youth"; "albinism OR albino"; and "mother* OR parent* OR rais*." During initial trials of the search strings, I discovered that by limiting the location to Tanzania, the results were too restricted. By broadening the location to include specific affected neighboring countries as well as the broader region and continent, I was able to capture more applicable and relevant results. Following each search, I exported all results from each database into Endnote™, a reference management software, using RIS file formats. A total of 270 articles resulted, of which 60 were duplicates.

This resulted in a total of 210 articles to screen using inclusion and exclusion criteria. Articles were included if they met the following criteria: peer reviewed journal articles, Masters' theses, or PhD dissertations; in English or French; substantive discussion of albinism; and explicit discussion of the mothering or parenting concept. Articles were excluded if they were not peer reviewed, not in English or French, did not mention albinism, mothering or parenting, and if they were a Bachelor's level thesis. Following this screening process, I selected 22 relevant articles that met all inclusion criteria.

The databases available for my search contain citations primarily from the Global North[1] versus the Global South. Therefore, to ensure I was capturing existing data on a global level, I performed an Advanced Google Search in addition to the databases used. As several thousand hits resulted, I scanned only the first four pages of the results list. This process identified 5 articles, 2 of which were duplicates from the database search, resulting in a total of 3 articles added for inclusion. Several chapters related to my topic were also included (these chapters are part of the broader program of research in which this study is embedded, as mentioned in Chapter One).

To further broaden my search and avoid overlooking valuable literature, I used backward/forward citation searches of the selected articles. I was able to identify another 8 articles relevant for this study that met all inclusion criteria. In total, 33 articles were included in this literature review (see Appendix B for Literature Review PRISMA [Moher et al., 2009]). In

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[1] The classifications of global South and global North are imperfect and come with exceptions (e.g., Australia and Namibia as high income and high-middle income respectively). However, for the purposes of the present report, they are useful in highlighting those regions where structural factors (lower resources) and higher incidences of albinism converge to create contexts of higher risk of human rights violations.

addition, I drew on Ero's UN reports as the UN Independent Expert on the enjoyment of human rights by persons with albinism. Notably, Kromberg, Zwane, and Jenkins' (1987) article entitled "The Response of Black Mothers to the Birth of an Albino Infant" is the only research article explicitly addressing the particular topic of mothers and mothering in relation to albinism, addressing the issue in South Africa.

After employing principles of Garrard's (2017) matrix method to perform a thorough literature review (see Appendix C for sample of literature review matrix), I used QSR International's NVivo™12 qualitative data analysis software to analyze the literature for relevant data. After uploading each article to the software, all articles were read and coded using various extraction questions (See Appendix D for the literature review codebook). These codes sought to gather data that articulated the following: the everyday lives and experiences of mothers of children with albinism; the support that they receive from family, their community, the government, and NGOs/CSOs; what access to health and social services looks like at the community, government, and NGO/CSO levels, as well as their access to health-related knowledge and education; the social influences on the experiences of mothering children with albinism, such as the SDoH and social constructions of womanhood; and, finally, threats to human rights and health, including myth and stigma, discrimination, gender-specific threats, and violence.

Synthesis of Literature

The following is a comprehensive discussion of current literature available on this topic which also articulates gaps in the current body of research that point to the necessity of this current research study. I begin by providing an overview of the literature included, as to

discipline of lead researchers, authors' country of origin, research locales addressed, and research methods used in their studies. Following a summary of the articles included in this literature review, I detail how, together, they provide a review of understandings contained in current research literature as to the experience of mothering, threats to human rights and health, and the social influences on the experience of mothering children with albinism.

Summary Information of Research Literature

A total of 33 sources met the criteria for this study. Methods were distributed as follows: qualitative ($n = 13$), quantitative ($n = 2$), mixed methods ($n = 3$), and systematic reviews and content analysis ($n = 3$). In addition, several selected sources use methods such as policy analyses, legal analyses, philosophic inquiry, and other non-empirical analyses ($n = 12$). Studies represented health (nursing, medicine, and public health), social sciences (anthropology, psychology, disability studies, cultural studies, and education), arts and humanities (critical arts, literature, and philosophy), and law. The earliest article was published in 1987, with the latest published in 2019. There were 24 sources published in the last 10 years. Most of the studies, 29, occurred in Africa (e.g., in Tanzania, Uganda, South Africa, Malawi, and Zimbabwe) with the exception of three which were conducted in the United States of America and Australia, and two of which had a global reach. While 29 sources were focused on or conducted in African countries, only 12 articles included a lead author from an African country. Similar results concerning Global South and Global North authoring were reported by Reimer-Kirkham et al. (2019) in their scoping review on albinism.

The Experience of Mothering

While discussion exists in the research literature around the struggles that families impacted by albinism face, little discussion is focused on the everyday lives of mothers of children with albinism. It is fascinating that what has been shown in the research literature to date are quite repetitive snippets of a mother's experience embedded within a growing volume of research literature exploring the broad, troubling albinism narrative in sub-Saharan Africa. Much less research addresses the experience of mothering in any kind of depth. Rather than a critique, this illustrates both the urgency of research and advocacy work to improve the lives of persons with albinism as well as the ways in which such crises invariably silence the experiences of those in close proximity. In order to begin to piece together what is currently understood in the literature regarding their everyday lives, I coded the research literature for discussion related to primary concerns and parenting struggles and strategies. Along with these concepts, I examined the research literature for the experience of mothering and albinism with the following codes: experience of women with albinism; experience of girls with albinism; experience of pregnancy of women with albinism; delivery of a child with albinism; postpartum period of a mother who has a baby with albinism; and partner or spousal support following delivery of a child with albinism. In the sections that follow, I summarize these themes.

A common thread identified throughout much of the research literature is the struggle that families with children who have albinism face in terms of health, safety and security, education, acceptance, and employment. Parents of children in sub-Saharan Africa with albinism often must weigh these concerns within the context of poverty, lack of access to key services, and lack of support and resources from their families, communities and governments alike.

Kromberg et al. (1987), in their germinal work in South Africa, described the response of black

mothers to their babies born with albinism. Acknowledging the various beliefs and myths

surrounding albinism in various African regions, Kromberg et al. (1987) hypothesized that "the

birth of an albino infant might well be a traumatic event for the mother, provoking emotional

confusion and interfering with the normal development of maternal-infant attachment" (p. 911).

The authors found that, in comparison to a control group of mothers whose infants were

unaffected by albinism, mothers of babies with albinism initially reported greater feelings of

depression, worry around the unhappiness of the infants' fathers, fears of rejection by their

community and family, and displeasure in the appearance of their infant. Further, Kromberg et

al. (1987) observed that mothers of infants with albinism showed less affection and connection

(e.g., holding their infant close, stroking them, singing to them, kissing them) in initial

observations than the control group. Authors also noted that significantly fewer mothers with

affected infants "want(ed) to hold or breast-feed their infants shortly after birth" (p. 912). These

observations seem to highlight the shock, even trauma, that women who deliver babies with

albinism experience in the initial postpartum period, a finding that more recent studies have

confirmed (Aquaron et al., 2009; Braathen & Ingstad, 2006; Duri & Makama, 2018; Estrada-

Hernandez et al., 2007; Kromberg, 2017; Lynch et al., 2014; Morris, Glass, Wessels, &

Kromberg, 2015). Essential to furthering this research, however, is the finding by Kromberg et

al. (1987) that these mothers show increasing connection to their infants over time—suggesting

that the bond is potentially more gradual as the shock of their infant's condition wanes and, as

the authors suggest, the realization that their child's cognitive and physical development is

unencumbered by their lack of pigmentation and affected visual acuity. Though not without

limitations, this study was the first and remains the only academic study dedicated to the experience of mothers who have children with albinism. It is this study, thirty-two years ago, that I am now building upon.

Kiishweko (2016) discussed the experience of women with children who have disabilities more broadly, including albinism, within patriarchal societies, asserting that women are disproportionately held responsible for the cause of their child's condition as well as for their care. Patriarchy and patrilineality were also noted by Brocco (2016), who articulated that while mothers were found to be more accepting and loving of their children with albinism, "the ultimate decision of whether or not to reject them lays in many cases in the hands of the father" (p. 234). Other researchers have found that many fathers of such children abandon their families, rejecting their partner/wife and child with albinism (Aquaron et al., 2009; Baker, Lund, Nyathi, & Taylor, 2010; Braathen & Ingstad, 2006; Brocco, 2016; Butler-Jones, 2013; Duri & Makama, 2018; Estrada-Hernandez, 2007; Kiishweko, 2016; Kromberg et al., 1987; Kromberg, 2017; Masanja & Magembe, 2015; Mulemi & Ndolo, 2014; Taylor, Bradbury-Jones, & Lund, 2019). According to Kiishweko (2016), a National Survey on Disability in Tanzania released in 2008, in which albinism was included, noted that "nine percent of children with disability under the age of 18 years lived without their fathers, as compared to 1.8 percent who were living without mothers" (p. 121). Duri and Makama (2018) cited a staggering 90% of children with albinism raised by single mothers in East Africa. Kiishweko (2016) further exposed systemic barriers that these mothers face due to "misogynistic structures which give women limited education and formal employment prospects" to begin with (p. 122). Such structures have a compounding

impact on mothers of children with disabilities that further deepens the intersectional experience of such women.

Faced with pressure by their partners, in-laws, community members, or midwives to abandon or even kill their baby born with albinism, women suffer the very present realities that generations of myth and stigma have created in understanding the humanity of the person with albinism (Duri & Makama, 2018; Lynch et al., 2014; Masanja & Magembe, 2015). Mothers who deliver babies with albinism, as mentioned above, are frequently left to parent alone, abandoned by the child's father, their in-laws, and their community (Braathen & Ingstad, 2006; Brocco, 2016; Butler-Jones, 2013; Duri & Makama, 2018; Kiishweko, 2016; Lynch et al., 2014; Masanja & Magembe, 2015; Taylor et al., 2019). In part, due to a woman's already inferior position within society, the risk to livelihood is acute (e.g., lack of education that would enable a woman to obtain gainful employment, life as a single mother of a child with a disability) (Duri & Makama, 2018; Kiishweko, 2016; UNGA, 2019a). In addition, there exist grave threats to their human rights, both to mothers and their children. The following section describes the current state of knowledge on threats to the human rights of mothers and their children with albinism, as well as the significance of introducing a human rights lens to research on albinism.

Threats to Human Rights and Health

To determine the current state of knowledge in the research literature on threats to the human rights of mothers and their children with albinism, and exploring how such threats directly impact overall health, I coded the research literature as follows: myth/stigma and health; discrimination and health; gender-specific threats and health; and violence and health. Of note, the language of "human rights" within research on albinism as a research aim, lens, or topic is

quite new (Reimer-Kirkham et al., 2019). Ikponwosa Ero's appointment as the UN Independent

Expert on the enjoyment of human rights by persons with albinism in 2015 has highlighted

human rights as foundational in all efforts to improving the lives of persons with albinism. By

applying a human rights lens to the current literature, I was able to discover various authors that

speak to human rights violations, although the explicit language was not frequently used until as

late as the year 2018, with Burke et al. (2014) being one of the first in this sample of the

literature to reference the phrase "human rights."

Related in large part to ongoing myths and spiritualized beliefs regarding the causes of

albinism and the value, or lack thereof, placed on a person with albinism, several threats to their

human rights exist (Burke, 2014; Franklin et al., 2018; Reimer-Kirkham et al., 2019; Taylor,

Bradbury-Jones, & Lund, 2019; UNGA, 2018). Various sources discussed widely held beliefs

regarding the causes of albinism, many of which are gendered in nature and represent a mixture

of biomedical knowledge with traditional and supernatural beliefs (Baker et al., 2010; Braathen

& Ingstad, 2006; Brocco, 2015; Bryceson, Jonsson, & Sherrington, 2010; Cruz-Inigo et al., 2011;

Franklin et al., 2018; Gaigher et al., 2002; Imafidon, 2017; Kromberg et al., 1987; Kiishweko,

2016; Mulemi & Ndolo, 2014; Reimer-Kirkham et al., 2019; Taylor et al., 2019; UNGA, 2017b,

2019a). Brocco (2016) found that where there were no relatives or ancestors of a child's parents

known to have albinism, the fault would lie on the mother alone and she and her affected child

would be rejected. Such causal myths include the belief that if a pregnant woman looks at

someone with albinism, her baby will have albinism unless she spits on the ground (Braathen &

Ingstad, 2006). It is also widely held that women who deliver babies with albinism are

themselves sick (Braathen & Ingstad, 2006; Brocco, 2016), have broken a taboo (e.g., becoming

pregnant during menstruation, laughing at another person with albinism) (Bradbury-Jones, Ogil, Betts, Taylor, & Lund, 2018; Gaigher et al., 2002), committed adultery with a white man (Kiishweko, 2016; Taylor et al., 2019), slept with an evil spirit ("*tokolosh*" in Shona tradition) (Baker et al., 2010), or are witches or cursed themselves (UNGA, 2016b). Such gendered myths further the intersecting discrimination that these women and their children with albinism encounter (e.g., gender, disability, colourism) (Kiishweko, 2016; UNGA, 2017a, 2019a). Held responsible for their child's condition (Brocco, 2016), which is widely seen as a bad omen or curse on the woman and her family, mothers impacted are confronted with sudden abandonment by partners, families, and communities (UNGA, 2016a, 2016b, 2019a). These mothers are frequently consigned to the fringes of society, either out of self-protection or by their community to ensure her and her children do not expose others to the curse of albinism (UNGA, 2016a, 2016b, 2019a).

Belief in such myths result in stigma and discrimination against mothers and their children with albinism and they are directly linked to human rights violations. Particularly disturbing is the belief that the body parts of persons with albinism hold supernatural powers and are therefore used in harmful witchcraft-related practices to produce potions or amulets believed to bring luck or good fortune to the possessor (Aquaron et al., 2009; Brocco, 2015; Cruz-Inigo et al., 2011; Imafidon, 2017; Lynch et al., 2014; Reimer-Kirkham et al, 2019; Shewedi, 2011; Taylor & Lund, 2008; Taylor et al., 2019). Such violent practices have fueled a market whereby contract killers traffic in the body parts of persons with albinism for a large profit (Burke et al., 2014, p. 118; Bryceson et al., 2010; Reimer-Kirkham et al., 2019; Taylor et al., 2019). As reported by Ero (UNGA, 2016a, 2016b, 2017b, 2019a), women and children with albinism are

disproportionately subjected to violent attacks, mutilations and murders. Gender-specific human rights violations exist to an alarming degree (UNGA, 2019a). These violations include reports of violence against mothers of children with albinism at the hands of spouses/partners as well as reports that women and girls with albinism experience sexual violence due to the myth that sexual intercourse with such a woman or girl will cure HIV/AIDS (Baker et al., 2010; Bradbury-Jones et al., 2018; Butler-Jones, 2013; Duri & Makama, 2018; Imafidon, 2017; Kiishweko, 2016; Pooe-Monyemore, 2007; Taylor & Lund, 2008; Taylor et al., 2019). This belief has not only left many women with albinism also infected with HIV/AIDS, but as Kiishweko (2016) noted, it raises concerns regarding their safety and freedom of movement—violating basic human rights. In Ero's report to the UNGA (2016b, 2019a), children are often targeted for their body parts for use in witchcraft-related practices due to the notion that their innocence enhances the powers of amulets or charms that are created. Mothers of such children are subjected to harassment, psychosocial distress, and violence as they attempt to protect their children from harm (Cruz-Inigo et al., 2011). Further, the poverty they face further exposes them and their children to insecure living environments where they become easy prey to such predators (UNGA, 2016, 2019a). As the burden of parenting largely relies on mothers, so does the fear of threats and attacks (Shewedi, 2011). This experience is circumnavigated by keeping their children close to home, at home, or at least near them as much as possible. In an effort to ensure their child's basic safety, parents of children with albinism may hide their children at home, avoiding the risk of sending them to school, work, or outside the home—resulting in further limitations to their freedoms (Baker et al., 2010; Burke et al. 2014; Franklin et al., 2018; Kiishweko, 2016; Morris et al., 2015; Shewedi, 2011; Taylor et al., 2019). Recently, innovative methods to protect persons

with albinism have been introduced. Mswela (2019) analyzed through a legal lens the part that

GPS tracking devices could play in protecting children. The suggestion is that parents would be

notified if their child with albinism leaves a certain "safe zone," allowing them to then notify

authorities and take swift action (Mswela, 2019). While ethical arguments exist surrounding the

use of GPS tracking methods (e.g., confidentiality and privacy) (Mswela, 2019), proposals of

such methods illustrate the everyday reality that mothers (and parents) face in identifying ways

to keep their children safe from harmful attacks. Widespread belief in myths around the causes of

albinism results in mothers and their children having to navigate such threats in the face of

poverty, threats to their human rights, difficulty obtaining health care, and various other SDoH

impacting their well-being (Reimer-Kirkham et al., 2019).

  While few authors of health-related research articles specifically discuss human rights or

employ a human rights framework to research or recommendations, Ero's reports to the UN

Human Rights Council, provide exactly this (UNGA, 2016a, 2017b, 2019a, 2019b). As Reimer-

Kirkham et al. (2019) identified, health researchers are increasingly incorporating a human rights

lens or framework into their research or analysis on the situation that persons with albinism face

in parts of the world (Bradbury-Jones et al., 2018; Burke et al., 2014; Franklin et al., 2018;

Mswela, 2019; Taylor et al., 2019). However, by and large, this uptake has been led by Ero. In

recognition of her mandate as the Independent Expert on the enjoyment of human rights by

persons with albinism, she has garnered support from various state actors, NGO and CSO

stakeholders, grassroots leadership, and international human rights activists to highlight the

concerns of persons with albinism the world over (UNGA, 2016a, 2017a, 2017b, 2018b, 2019a).

Social Influences on the Experience of Mothering Children with Albinism

In this section I explore the social influences that impact mothers of children with albinism, including the social constructions of gender/womanhood and various SDoH. These concepts were identified in the research literature using the following codes: social constructions of womanhood; faith, spirituality, and religion; and SDoH. Poverty, gender, disablism (discrimination), sociocultural views (myth and stigma), physical location, availability of health and social services, education, and employment are the SDoH that I focused on when coding the literature. Such influences are fairly well documented in the research literature as they pertain to people with albinism; however, there is a paucity of evidence as to how such outside influences impact mothers and the experience of mothering children with albinism. This current study adds to the evidence regarding such experiences.

Social constructions of gender/mothering. Brocco (2015) asserted that regardless of the mother having albinism herself, "the most important element of the dowry that a bride-to-be has to assure is that she will give birth to healthy (and black) children" (p. 1148). Other authors (Brocco, 2015; Hudson-Weems, 2019) noted that within much of African culture, marriage and family is paramount, particularly for women. Directly related to generations of myth and superstitious beliefs attached to albinism, this expectation is disrupted when a woman delivers a baby with albinism, particularly if neither parent has albinism themselves (Aquaron et al., 2009; Brocco, 2016; Duri & Makama, 2018). Unless there is a clear and known link to albinism within the ancestral family line of either the mother or father, Brocco (2015) noted that the blame rests on the mother who is then labeled a "'sick person' (*mtu mgonjwa/watu wagonjwa*)" (p. 1148). This gendered belief creates enormous potential for disparities in the health of women and their

children impacted by albinism. While there are references to mothers abandoning their children with albinism (Masanja & Magembe, 2015), Bryceson et al.'s (2010) study provided the counter-narrative of a mother who, pressured to abandon or murder her son with albinism, fled her husband and home community to find refuge somewhere safer. Such narratives exist at a clear risk to the livelihood of mothers who, fleeing their unsupportive partners and communities, face mothering alone without support and in the face of poverty. Duri and Makama (2018) found that women with albinism and women who give birth to children with albinism "are the worst affected" in terms of negative sociocultural experiences, asserting the interplay of misogyny and its detrimental effects on mothers who are blamed for the birth of affected children (p. 82). Duri and Makama (2018) noted that fewer females with albinism go on to marry than males with albinism; even fewer marry black men in comparison to males with albinism who marry black women. This discrepancy must impact the way in which girls with albinism are raised and the level of concern that parents carry regarding their daughters' future livelihood given the strong expectation placed on marriage and family, particularly for women.

Kiishweko's (2016) dissertation detailed the experiences of mothers of her participants with albinism. Her findings suggest that mothers of children with albinism experience their mothering as "hurting," as "sacrifice," as "exclusion," and as "loneliness" (p. 122). As noted above, childbirth and mothering are central to the role of a Tanzanian woman (Brocco, 2015). Describing traditions in Tanzania around childbirth, Kiishweko (2016) noted the community celebration that is typical. Childbirth brings "joy and happiness to family members, neighbors, friends, and relatives" (p. 122). However, in the presence of albinism, quite the opposite is found: Myths and belief suggest that just by looking at a person with albinism can bring the

"curse" to your own family (Kiishweko, 2016). Poignantly, Kiishweko (2016) described this as "a vice versa type of experience where [mother] and her children stain and contaminate each other. This can mean that emotions of hate that stick on albinism…can instigate misogyny, which always sticks on women" (p. 122).

      Poverty. As is becoming apparent, researchers highlight the close interrelationship of poverty (socio-economic status) and albinism (Estrada-Hernandez, 2007). Brocco (2016) stated that "most of the people with albinism in the study were living in a state of severe poverty and vulnerability" (p. 240). This is affirmed in much of the other research literature (Braathen & Ingstad, 2006; Cruz-Inigo et al., 2011; Estrada-Hernandez et al., 2007; Kiishweko, 2016; Lynch et al., 2014; Masanja & Magembe, 2015; Shewedi, 2011; Taylor & Lund, 2008). Masanja and Magembe (2015) described the impact of poverty on the whole family, noting how it impacted the concept of "hope for a better future" in their participants impacted by albinism (p. 97). Indeed, living within such persistent myths and negative beliefs about albinism impacts various levels of one's sense of self and ability to plan for the future. Mothers impacted by albinism are acutely impacted by poverty upon the abandonment of their partner, faced with being thrust into the position of sole breadwinner. This poverty impacts a mother's ability to provide basic needs such as shelter, food, and security along with education and access to health needs (Brocco, 2016; Kiishweko, 2016; Shewedi, 2011). Kiishweko (2016) described the "feminization of poverty" and the connection to "mothers' financial struggles to support their [children's] educational needs" (p. 128). For example, Kiishweko (2016), with a story about a daughter with albinism who is illiterate, argued that this is not representative of a mother's irresponsibility, but

rather it is the interplay of chronic poverty, lack of support, and misogyny that creates the position that mothers of children with albinism are in (Kiishweko, 2016).

Bryceson et al. (2010) and Burke et al. (2014) foregrounded the broader, capitalist underpinnings at play in the relationship between poverty and violence against persons with albinism. Bryceson et al.'s (2010) exploration of the mining boom in Tanzania as impacting the human right to life of persons with albinism provided the exemplar of Burke et al.'s (2014) argument regarding widening inequities and structures of power. They argued that "oppression of [persons with albinism] cannot be understood only as arising from traditional beliefs, but also emerges for structural reasons which are related to rapid change and new forms of inequity in wealth and power" (p. 119). This argument must also include gender and the manners in which power and privilege is largely afforded to men in the society, regardless of whether they stay with their family impacted by albinism or not.

Access to education. Many authors have contributed to a substantial discussion in the research literature related to concerns around access to education for persons with albinism. While little of this discussion centres around how *mothers* of children with albinism experience this access, or lack thereof, there are several insights that help to inform the study at hand. In order to assess the research literature for this theme, I coded relevant details to the code "access to education." The following summarizes this access.

Concerns around education for children with albinism are often written about in the research literature. There is discussion around the lack of appropriate resources and specially trained teachers in mainstream, local schools (Gaigher et al., 2002; Kromberg, 2017; Masanja & Magembe, 2015; Pooe-Monyemore, Mavundla, & Christianson, 2012). Various authors noted

the financial burden of sending children to school, citing the cost of protective clothing and

supplies (Kiishweko, 2016; Shewedi, 2011). Even more, the cost of sending their children to a

private school (e.g., a school for the visually impaired) where there are resources such as visual

aids and teachers that are knowledgeable regarding the particular needs of students with albinism

can be prohibitive (Brocco, 2016; Lund & Gaigher, 2002). As already discussed, mothers and

families impacted by albinism are making key decisions in the context of poverty (Brocco, 2016;

Franklin et al., 2018). Without access to suitable education, future employment opportunities for

children with albinism often remain limited to manual labor outdoors which further exposes

them to the harmful effects of the sun (Brocco, 2016).

The decision to send their children with albinism to school is multilayered and parents

must take into consideration their child's safety in terms of walking to and from school (Franklin

et al., 2018), safety while at school, cost and quality of schooling, as well as the location of

schooling (Burke et al., 2014; Kromberg, 2017; Lund & Gaigher, 2002; Lynch et al., 2014).

Parents are often confronted with teachers who know very little about albinism and the low

vision and skin risks that are associated, resulting in unacceptable care and protection provided

to their children in mainstream schools (Kromberg, 2017). Baker et al. (2010) noted that access

to special schools for visually impaired learners provides a well-supported environment that is

equipped with necessary visual aids and educators aware of the low visual acuity that

accompanies albinism. The concern is that without these supports, students face a number of

practical barriers in mainstream schools that lack necessary provisions (Baker et al., 2010). Lack

of infrastructure in rural areas due to chronic poverty prevents support measures in local schools

to ensure children with albinism have the education and services they require to succeed

(Gaigher et al., 2002). Children with albinism often face discrimination within the school from teachers and peers alike, resulting in an unsafe environment in which their opportunities to thrive academically are threatened (Baker et al., 2010; Kiishweko, 2016; Pooe-Monyemore, 2007). Pooe-Monyemore et al. (2012) articulated the impact that educators who are knowledgeable about OCA 2 have on a student's sense of self, belonging, and their development. Along with a child's family, teachers can provide key support for children with albinism.

Some mothers engage in "hiding behaviors" to protect their children from attacks, thus preventing them from attending government day schools (Burke et al., 2014; Franklin et al., 2018; Shewedi, 2011). For these reasons, many parents choose to send their children to government holding centres (discussed in depth in Chapter Five) or boarding schools (both referred to in the literature as "residential resource centres," "camps," or "special schools") for children with disabilities, many of which are sponsored and promoted by the government or NGOs, in locations that are deemed to be safer (Burke et al., 2014; Franklin et al., 2018; Lund & Gaigher, 2002; Lynch et al., 2014). These government holding centres were initiated by the government in response to the vicious attacks on persons with albinism and what were to be temporary shelters have now become more permanent homes for these children. However, as noted by Burke et al. (2014), the impact on families and children separated by such schools or camps specifically in Tanzania has not been given enough attention. While improving security in some ways, the practice has also created other concerns including overcrowding of facilities, child abuse, and neglect and abandonment of children by their families (Burke et al., 2014). There are various challenges to this strategy as a sustainable solution (Burke et al., 2014; Franklin et al., 2018; Masanja & Magembe, 2015). While it may provide temporary physical

security, this separation/segregation leads to "loss of other freedoms and rights, such as family life, engagement in the community or freedom of movement" (Franklin et al., 2018, p. 6). Masanja and Magembe (2015) asserted that this separation could lead to "a generation gap in which family and community values are never passed on to the concerned children" (p. 105). Such concerns were addressed by Burke and colleagues (2014) as well.

        Notably, Kromberg (2017) and Masanja and Magembe (2015) addressed the positive impact of parents educating their children early on and throughout their development about their albinism condition. This is shown to empower children with their own understanding of their condition, enabling them to educate their peers and others around them to counteract stigmatization. Kromberg (2017) further suggested that "such knowledge may result in a better self-concept in the affected person" (p. 177). Mothers in Kiishweko's (2016) dissertation research were identified as figures of support and encouragement to obtain as much education as possible, even as they faced poverty. In interviews with university students with albinism, Kiishweko (2016) found that these participants recognized that once their mothers had been abandoned by their fathers, their mothers struggled to raise them as single parents. Participants, as grown children with albinism, offered that their mothers often had little to no formal education themselves, "with an income too unstable to adequately fund their daily basic requirements, let alone their school requirements" (p. 121). This finding is again representative of the (non)choices that mothers face when navigating mothering in the context of poverty. Kiishweko (2016) detailed that mothers in her study were unable to provide adequate "home learning environments or facilities that would support [their child's] education" (p. 121). Again,

Kiishweko (2016) highlighted such lacks as driven by "misogynistic structures which give women limited education and formal employment prospects" (p. 122).

      Access to health and social services. To identify how the current research literature has discussed how mothers of children with albinism access health and social services, I coded literature under the following themes: access to health and social services that is government led; access to health and social services that is NGO and/or CSO led; and access to health-related knowledge and education. As this study focused on the experience of mothers, particular energy was given to search for details regarding how mothers who delivered a child with albinism were equipped with health knowledge at the time of delivery and/or at the time of hospital discharge. In the following section, I summarize evidence related to how mothers access health and social services for their families.

      Poverty, again, and lack of consistent health care and social services subsidized by governments are identified as key prohibitive factors in accessing health care, lifesaving sunscreen, and protective clothing and hats for their children (Shewedi, 2011). Beginning at delivery, Braathen and Ingstad (2006) noted in their study in Malawi that not one mother was given an adequate explanation of why their child had been born with albinism and only a few were told to keep their child out of the sun. Further, the prohibitive cost of sunscreen coupled with access to information on using it effectively is routinely mentioned in the research literature, with families using it sparingly or only a few days a week (Braathan & Ingstad, 2006; Butler-Jones, 2013; Cruz-Inigo et al., 2011; Taylor & Lund, 2008;). Butler-Jones (2013) identified in her study the prohibitive cost of other necessary health-related needs including eye care (e.g., assessment and eye glasses) and HIV/AIDS treatment, particularly related to the false

belief that sexual intercourse with a woman with albinism can cure HIV/AIDS. Mobile skin and

vision clinics organized by NGOs/CSOs remain a staple in reaching affected families,

particularly in rural areas (Cruz-Inigo et al., 2011). Baker et al. (2010) noted the burden placed

on families in light of this lack in health and social service structures. Pooe-Monyemore et al.

(2012) called for the government departments of health and education to ensure families are

equipped to deal with the condition, by providing ample sunscreen, access to regular vision care

and dermatology assessments, and ongoing health education about, at a minimum, the condition.

This was echoed by participants in the study by Bradbury-Jones et al. (2018) asking for more

government support to best care for their children with albinism. Kiishweko (2016) detailed the

distance that mothers must go to obtain adequate health care for their children with albinism:

"[S]everal kilometers by foot to take Rita to an eye clinic that was specifically for school

children with albinism…Rita had been receiving limited health attention at the village clinic she

was attending" (p. 125). Existing healthcare services may not be adequately equipped to provide

particular care for persons with albinism.

Some authors argued for genetic counseling services to be mainstreamed. Morris et al.

(2015) highlight in their study the need for mainstream genetic services that are well advertised

and easily accessed by families impacted by albinism, a service that is advocated for by mothers

of children with albinism in their study. Ehlers (2002) and Baker et al. (2010) viewed this as an

important opportunity for genetic nurses to be trained and mobilized to provide services to new

mothers of infants with albinism, providing women with as much information about the

condition as possible. Further, Ehlers (2002) argued, from a South African health policy

perspective, that the work of genetic nurses could further assist changing social beliefs about

albinism, particularly in a timely fashion following the delivery of a child with albinism. Affirming this, Baker et al. (2010) asserted that genetic counselling would be empowering to mothers who face the burden of counteracting negative myths and beliefs that she will confront from her own community and society at large. Of note is the manner in which this call for genetic nurses or counsellors contrasts sharply with current accounts of healthcare providers operating under the very negative myths and beliefs harmful to persons with albinism (Imafidon, 2017). Such accounts include nurses and hospital staff who are unwilling or afraid to touch children with albinism who present in need of healthcare (Baker et al., 2010). Imafidon (2017) calls for healthcare providers to be better equipped to help families and individuals impacted by albinism address the various health-related concerns as well as to dispel myths and beliefs. Most notably, Imafidon (2017) suggests this should be achieved by both willful engagement on the part of providers or made compulsory by government mandate. However, there appears to be little promotion of genetic counselling outside of the South African context. While Imafidon (2017) calls for "counselling" in each health centre, genetic counselling is not explicitly discussed. Components of genetic testing (e.g., laboratory testing) and prenatal genetic counseling do not appear to be championed broadly within the African context.

As noted by Lynch et al. (2014) in their research in Malawi, "families who had access to the right clinical services, schooling (e.g. resource centres) and advice (TAAM) felt better placed to make decisions about their children's physical and emotional well-being and education" (p. 230). Such support and resources equip parents with necessary strategies to best support their children with albinism to thrive at each developmental stage. Notably, Pooe-Monyemore (2007) identified the "significant role of mothers in the nuclear family" to advocate for their children

with albinism in terms of health and education (p. 87). This echoes key aspects of Africana Womanism, in which family-centrality and the advocacy work of mothers, including the power of a mother's voice, are valued, celebrated, and revered (Hudson-Weems, 2019).

Recent research out of the United States of America (USA) by Corn and Lusk (2018a, 2018b) suggested that even in the Global North, parents may not receive timely information regarding vision screening and are not provided with detailed information regarding their child's functional visual acuity. Recommendations by Corn and Lusk (2018a, 2018b) included ensuring that general practitioners provide parents with the necessary health information and direction to resources (such as NOAH). This research highlighted that, despite infrastructure and medical advancements in the USA, not every family impacted by albinism is accessing resources equally. In some part, this is due to lack of knowledge by healthcare practitioners. However, the disparities are stark when we compare the North American context to that of sub-Saharan Africa, where most of the research literature stems from.

Support for mothers and their children with albinism. Much of the current research explores support for persons impacted by albinism from a health care, education, and NGO/CSO perspective. As already described, there is limited discussion around parenting and parenting as a single mother. In the following section, I describe the evidence that relates to how mothers of children with albinism and their families experience outside support, generally as well as in terms of specific resources available. Using the following codes, I captured themes within the research literature that relates to such support: family dynamics (e.g., how mom and baby are treated by family and in-laws); receptiveness of the community; community support; government support and resources; and NGO/CSO support and resources.

Some researchers have studied how mothers of children with albinism regularly face negative reactions (as those already described above), with fewer findings related to support received. Brocco (2016) identified how mothers garner support within their families and amongst in-laws when an elder, particularly the grandfather, identifies the child with albinism as looking like other relatives in the family line. When linked to lineage, it appears that mothers have a fighting chance at obtaining support within their families. However, when no relative on either side is identified as having had albinism, mothers face the reality of accusations leveled against their behavior (Brocco, 2016).

Braathen and Ingstad (2006) noted the unwavering love of mothers in their study for their children with albinism despite discrimination and ostracism by their community and strangers alike. However, they noted that these negative responses sometimes improved over time, giving way to some semblance of acceptance, which could be interpreted as support (Braathen & Ingstad, 2006). Butler-Jones (2013) in her dissertation on the impact of resilience of persons, particularly women with albinism, found that women identified "most of their suffering was the result of external forces, and the greatest cause of their suffering was people in their respective communities" (p. 50). The need to belong alongside the concept of group support was highlighted in Butler-Jones' (2013) research, including a desire to form a women's support group. This finding in the current research literature provides the most explicit reference to women-specific support, to date, even though this was suggested in terms of women with albinism and not necessarily mothers of children with albinism.

Similarly, albinism societies were identified by researchers as sources of support more generally (i.e., not discussed in terms of supporting mothers specifically) (Gaigher et al., 2002).

In terms of support potentials within faith communities or other community-based organizations, Brocco (2016) identified that such belonging can "contribute to the formation and transformation of the subjectivities of people with albinism with regard to the creation of a group identity" (p. 240). Again, this conclusion is not linked specifically to mothers impacted by albinism, but certainly suggestive of support networks that benefit all parties impacted by albinism.

Educators were also identified as key sources of potential support for children with albinism and, thereby, their families. Lynch et al. (2014), Bradbury-Jones et al. (2018), and Shewedi (2011) identified the potential of teachers in a supportive role, especially when equipped with professional development strategies. Investing in teachers who are counselled on how to best support children with albinism in their classrooms assists to increase the self-esteem and self-concept of children with albinism (Pooe-Monyemore et al., 2012; Taylor et al., 2019). Indeed, the common denominator in the research literature is for further support directed to all affected and all in helping roles (Baker et al., 2010; Burke et al., 2014; Cruz-Inigo et al., 2011).

Chapter Summary

In this chapter, I have synthesized the existing research literature related to the experience of mothering children with albinism in Tanzania. With the help of a library scientist, I conducted an extensive search of various databases to ensure that all relevant research was reviewed for inclusion in this literature review. Using QSR International's NVIVO^{TM} 12 software, I coded the literature to answer key questions relating to the study objectives. Kromberg et al. (1987) provided the singular article whose purpose was to research how mothers experienced the birth of a child with albinism. I detailed how various literature speaks to similar themes, with only a few (e.g., Kiishweko, 2016) delving into the particulars of the mothering experience beyond

Kromberg et al.'s (1987) germinal work. This chapter provides the rationale for conducting

further research specific to the experience of mothers impacted by albinism. In the following

chapter, I describe the research methods used in this focused critical ethnography exploring the

social influences on the experience of mothering children with albinism in Tanzania.

Figure 2. View from the car window navigating narrow, dirt roads washed out by heavy rains.

Deep crevices in the roads made passage nearly impossible at times between interview sites.

Inadequate infrastructure such as roadways throughout Dar es Salaam and Mwanza highlighted

the risk to safety and security for families impacted by albinism. In difficult-to-reach areas,

escape or emergency response systems are hampered.

Chapter Three: Research Methods

The purpose of this ethnographic study was to explore the social influences on the experience of mothering children with albinism in Tanzania. In Chapter Three, I will describe the research methodology undertaken to address the purpose and objectives of this study. Specifically, I outline the study design, sampling strategies, sample description, data collection procedures, and analysis. I conclude the chapter by describing efforts to ensure and account for scientific quality and credibility, discussing researcher reflexivity and positionality, offering the limitations of this study, and reviewing ethical considerations undertaken both in and out of the field.

Research Design and Methodology

Due in large part to the dearth in research related to the specific lived experiences of mothers of children with albinism in sub-Saharan Africa, a qualitative approach was deemed suitable for examining this phenomenon. Because of the attention required to culture and exploring tacit, insider knowledge, I chose an ethnographic research approach, namely focused critical ethnography (Streubert & Carpenter, 2011; Wolcott, 1999). In consultation with my thesis committee, Africana Womanism (Hudson-Weems, 2019) was also drawn on for its particular attention to power structures, intersectionality, culture, and inequities.

Ethnography

Considered the oldest method of qualitative research, ethnography is rooted in anthropology and is used as a tool for the discovery of cultural knowledge (Streubert & Rinaldi Carpenter, 2011). Ethnography was a response to the inadequacies of traditional science as researchers needed a method "of studying groups of individuals' lifeways or patterns" (p. 167).

Spradley (1980, as cited in Streubert & Rinaldi Carpenter, 2011) noted that ethnography went beyond studying people: Rather, "ethnography means learning from people" (p. 168). This principle is directly in the line with my values at the core of this study. The methodology has several schools of thought: classical, systematic, interpretive or hermeneutic, and critical (Streubert & Rinaldi Carpenter, 2011).

As this study aimed to acknowledge and address the intersectional experience of women impacted by albinism as well as "address the historical, social, political, and economic dimensions" that are part of creating such experiences, using the particular method of critical ethnography was imperative (Polit & Beck, 2017, p. 480). Critical ethnography is distinct from other ethnographic approaches in that its focus is "on raising consciousness and aiding emancipatory goals in the hope of effecting social change" (p. 480). With growing conversation occurring on national and global scales regarding the human rights of persons with albinism in sub-Saharan Africa (Franklin et al., 2018; Reimer-Kirkham et al., 2019; UNGA, 2016a), this study adds to the literature the intersectional experiences of mothers of children with albinism in an effort towards addressing the human rights of persons with albinism and their families. To identify that this study centres on a small population concerning a very particular concern in the specific context of Tanzania (Dar es Salaam and Mwanza to be more specific), the term "focused" is added to the methodology (Streubert & Rinaldi Carpenter, 2011).

Africana Womanism

As noted by Streubert and Rinaldi Carpenter (2011), central to "the qualitative research paradigm" is the focus to understand rather than "to explain, predict, or control outcomes" (p. 11). Particularly in critical ethnography, choosing a theoretical framework that considers both

culture and history in its theoretical underpinnings is important. Hudson-Weems (2019), in response to what she and other scholars of colour agreed was a largely white feminist movement that had exploited the struggle of women of colour to advance their ideology versus incorporate and genuinely consider the particular experience of the Africana woman, introduced her theory of Africana Womanism in the late 1980s with her first publication in 1989. Africana Womanism predated Crenshaw's (1989, 1991) "intersectionality" theory, having already explored the limitations of the gender-central theories available at that time, particularly to women of colour. Central to Africana Womanism (Hudson-Weems, 2019) are gender, race, and class. As Hudson-Weems (2019) asserts:

> Africana Womanism was designed to name, define and refine an authentic paradigm explicating the role of the Black woman within her historical and cultural Afrocentric family-centred matrix. On the other hand, feminism, and its current evolution from gender exclusivity to intersectionality, was designed for and by White women. (p. 109)

In this way, family is acknowledged and honored as central and men, rather than identified as oppressors of women, are embraced as co-partners in the Africana struggle of inequity and injustice based on racism and classism (Hudson-Weems, 2019). Considering the centrality of family and mothering to Hudson-Weems' Africana Womanism, this framework provides a "particular set of guiding principles" from which to understand the phenomena at hand (Streubert & Rinaldi Carpenter, 2011, p. 11). Figure 3, below, offers Hudson-Weems' (2019) illustration of the eighteen characteristics highlighted in her framework (further expounded upon in Chapter Six). Most importantly, Africana Womanism is affirmed by African scholars within the African context, such as the Zimbabwean scholars Muwati, Gambahaya, and Gwekwerere (2011), as a

theory grounded in "knowledge and values derived from the African people's cultural experience" (p. 1). Further, this framework fits well within the Tanzanian context and challenges me as a White, North American researcher to consider participants' experiences from a paradigm different than my own. Hudson-Weems (2019) affirms this fit, stating, "Africana Womanism is an ideology created and designed for all women of African descent. It is grounded in African culture, and therefore, it necessarily focuses on the unique experiences, struggles, needs, and desires of Africana women" (p. 24).
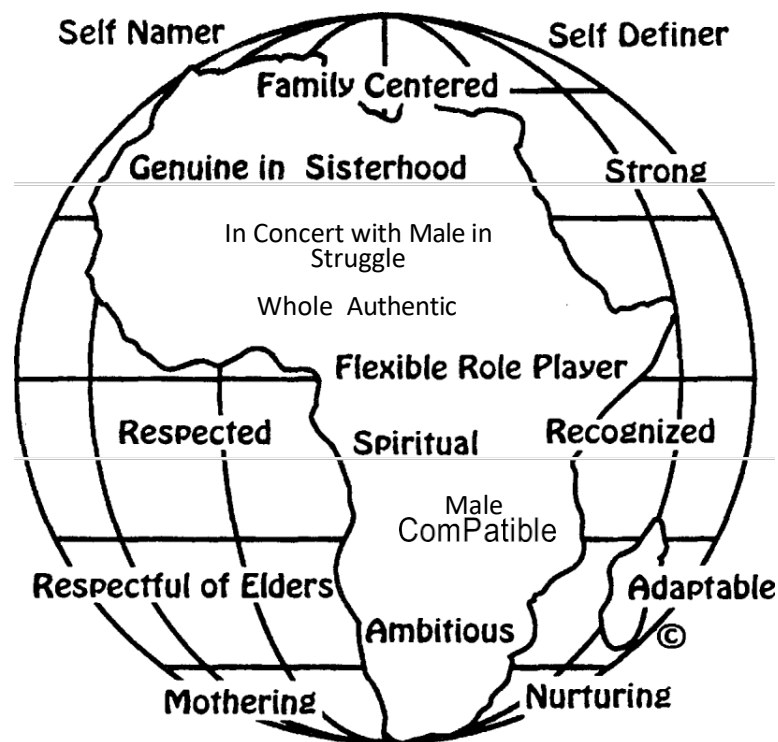
Figure 3. Africana Womanism. Hudson-Weems' (2019) illustration of the eighteen characteristics identified within her theoretical framework.

Trauma-Informed Research

Nursing continues to explore and adopt, in various practice and educational settings, the principles of trauma-informed practice (or care) (Cannon et al., 2020; Stokes, Jacob, Gifford,

Squires, & Vandyk, 2017). Some argue that its principles are embedded in the very heart of

nursing (Stokes et al., 2017) and, further, are well situated within population health science,

shifting "the focus from clinical practice to the development of trauma-informed programs,

systems, and policies" (Tebes, Champine, Matlin, & Strambler, 2019, p. 495). Embedding

trauma-informed frameworks into research methodology is a natural step, particularly when we

consider how "research is involved in the 'design of systems' " (Day, 2018, para. 8; Tebes et al.,

2019). Carello and Butler (2015) suggest that to be trauma-informed, in any context,

> [I]s to understand the ways in which violence, victimization, and other traumatic
>
> experiences may have impacted the lives of the individuals involved and to apply that
>
> understanding to the design of systems and provision of services so they accommodate
>
> trauma survivors' needs and are consonant with healing and recovery. (p. 264)

Considering the structural vulnerability of mothers impacted by albinism and, certainly, of

persons with albinism themselves, the absolute need to engage systems and policies that threaten

to traumatize and re-traumatize is obvious: Any research engaging with this community must

tend to methods of trauma-informed practice just as a health practitioner must when providing

direct care. Carello and Butler (2015) cite five principles to guide such practice: safety,

trustworthiness, choice, collaboration, and empowerment. The Substance Abuse and Mental

Health Services Administration (SAMHSA) (2017), in their brief on "building resilient and

trauma-informed communities," adds peer support and history, gender, and culture (p. 1). These

principles apply seamlessly to qualitative research methodologies, particularly this critical

ethnography of which it is an anchoring lens. Shimmin, Wittmeier, Lavoie, Wicklund, and Sibley

(2017) assert that applying "intersectional analysis" alongside a trauma-informed lens to research

methodology, the "binary categorization of 'patient' or 'public' and 'researcher' is exposed revealing spaces where power can be resisted and renegotiated"—strengthening trust and resiliency on both sides (p. 4). I believe this was well achieved by using Africana Womanism (Hudson-Weems, 2019), which locates the roles of race, class, and gender along with cultural and colonial histories as the guiding lenses from which to enact this research.

Setting: Describing the Fieldwork

With an invitation from *NGO-1* to conduct this study for its potential to evaluate and influence their programming for mothers of children with albinism, data was collected via focused critical ethnographic fieldwork in Tanzania over two separate trips. The first field visit was for six weeks from March to May 2019 and the second was for four weeks from October to November 2019. Fieldwork in Tanzania was divided between two regions: Dar es Salaam, the largest city and formal capital on the shores of the Indian Ocean in Tanzania, and Mwanza, a region located on the shores of Lake Victoria in Tanzania with both city and rural environments (see Figure 4 for a map of Tanzania). These regions provided both urban and rural perspectives. The variation between key stakeholders and mothers from two distinct locations in Tanzania ensured adequate data with a diversity in responses that lent itself to rich analysis and interpretation.

On arrival, I spent the first few days acclimating to the tropical heat of Dar es Salaam, adjusting to the new time zone, and becoming acquainted with the Tanzanian context by visiting with colleagues and establishing rapport at our partner NGO office, exploring the city via *bajaji* (i.e., small, three-wheeled taxis), eating Tanzanian cuisine (e.g., *chips mayai* [French fry omelet], tilapia with *ugali* [a thick polenta-like starch made from cornmeal], and barbecued goat meat),

and drinking a lot of orange Fanta and water to combat the heat and dehydration. These

experiences all occurred alongside staff at our partner organization who graciously laughed their

way through each one with me, keen to help me learn more Kiswahili. With several blunders

along the way, these colleagues were gracious with me and generous with their knowledge and

experience. I maintained an ethnographic mindset by reading local newspapers (those that were

in English), listening to local music, watching local news broadcasts, reading African literature,

and engaging with taxi drivers, shopkeepers, and the general public as much as I could.

Figure 4. Map of Tanzania. Stars indicate locations of fieldwork in Mwanza and Dar es Salaam.

(Freeworldmaps.net, 2020)

Describing Data Collection

Data collection consisted of participant observation with extensive fieldnotes, engaging

in sharing circles and semi-structured interviews. Related in part to the nature of engaging

mothers from the mamas'[2] groups as well as the communal context in which this research situates itself, the term "sharing circle" was chosen over "focus group" to describe the setting of the interviews. The method of sharing circles in this context has also been used by other researchers in this field, including Bradbury-Jones et al. (2018). Semi-structured interviews allowed for flexibility (see Appendix E for English and Kiswahili interview guides). Although there were questions to guide sharing circles and one-on-one interviews, as Streubert and Rinaldi Carpenter (2011) assert, "the opportunity for story telling is inherent in the format" (p. 34). Interviews were conducted in approximately one-hour intervals at mutually agreed-upon locations (e.g., mamas' homes, location of mamas' groups, cafes, places of work, and partner organizations' offices). Due to the very present nature of ethnography, I was prepared for both impromptu and planned sharing circles and interviews. Both were recorded using a digital recorder, with transcription by a transcriptionist (see Appendix F for transcriptionist confidentiality agreement).

Due to the language barrier, I conducted the fieldwork alongside a cultural liaison, Waithera, identified by the UN Independent Expert on the enjoyment of human rights by persons with albinism, who provided translation of informed consent materials as well as interpretation during interviews (see Appendix G for interpreter confidentiality agreement). Waithera and I worked closely alongside each other throughout most of my initial six-week visit. She was

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[2] In Kiswahili, the official language of Tanzania, the word for mother is "mama." Mothers are referred to using their title as "mama" followed by the name of their firstborn child or the name of the child in discussion (e.g., Mama Lightness). Throughout my thesis I will refer to mothers as mamas and to the mother's groups I engaged with as mamas' groups. Not only is this how our partner organization refers to them, this is how they refer to each other and to their own groups.

pivotal in planning interviews and sharing circles with mothers and key stakeholders. Throughout interviews, Waithera and I, using the semi-structured interview guide, consulted with each other about the direction the interview was taking. In this way, Waithera and I co-created how interviews and sharing circles unfolded. Because Waithera was able to translate language and context and we were both aware of tone and body language, we were able to shift the sequence, format, and direction of any given interview or sharing circle. This is to say that we both remained flexible from the beginning of an interview through to the end. As a woman with albinism herself, Waithera brought with her the ability to immediately connect with mothers impacted by albinism. Waithera's warmth, sense of humor, command of the context, and desire to see this study succeed for the benefit of women impacted by albinism is a large part of this study's success. Waithera's ability to bring me into the trust she established with the study participants enabled us to gather a richness of data otherwise unattainable. Our intention together was to create safe, sacred space to explore the life journeys of these women. Following each interview, Waithera and I extensively debriefed what was discussed, what we might have done differently, ideas for subsequent interviews, and, most importantly, fleshing out key topics and their context to ensure understanding on my part.

I maintained a diligent reflexive journal both prior to fieldwork, as "before entering the field to conduct interviews, researchers have to be open to their influence on the inquiry," and throughout the remainder of the study (Streubert & Rinaldi Carpenter, 2011, p. 34). Extensive fieldnotes were taken to capture the social and contextual influences at work and to prompt reflexivity. A fieldnote guide was used (see Appendix H for fieldnote guide) which adhered, as much as possible, to the *"language identification principle"* in which "ethnographers identify in

whose language the text is written" in order to not "lose sight of the cultural meaning of the observation" (p. 184-185). Essentially, this means that my fieldnotes differentiated between my observations/experiences and what was described or relayed to me and by whom (see Appendix I for sample fieldnotes). In addition, photos were taken to capture aspects of the everyday lives of mothers and their children, taking care to ensure anonymity (i.e., photos of participants are not identifiable). For example, I took pictures of the meeting space where the mothers' group is held, the NGO offices, and at the health centre and school.

Throughout fieldwork, ongoing conversation and communication via email, WhatsApp phone calls, and secure web conferencing occurred with Drs. Reimer-Kirkham and Astle. These committee meetings consisted of reviewing data collection strategies and methods, refining the interview guide and strategizing the use of time in the field with partners and with participants. Both formal and informal in nature, the opportunity to reach out to them, not only for their expertise and guidance, but to reflect on the work in real time, was invaluable to my process as researcher.

Recruitment and Sampling

The sample for this thesis is a subset of the larger team project referenced in Chapter One, and involves mothers impacted by albinism and key stakeholders. Purposive sampling methods for key stakeholders were used to ensure substantive, rich data (Polit & Beck, 2017). Inclusion criteria for key stakeholders included the following: either a person from Africa with albinism themselves, or a parent of a child with albinism; or an academic/activist/advocate who has worked alongside persons with albinism and/or conducted research specifically regarding the experience of persons with albinism in sub-Saharan Africa. In terms of exclusion criteria for key

stakeholders, participants were excluded if they had not worked alongside persons with albinism and their families or if they had not researched social experiences of persons with albinism. For mothers, inclusion criteria included the following: identifies as a mother or key caretaker of a child with albinism. Exclusion criteria for Tanzanian mothers: does not identify as a mother or key caretaker of a child with albinism.

My first research participant was a key stakeholder in attendance at a roundtable at the UN in Geneva organized by Drs. Reimer-Kirkham, Astle, and Ero to set a research agenda on human rights and albinism. As I was there in the capacity of research assistant in the broader program of research, I was able to utilize this opportunity to obtain an important interview. All other interviews took place once I arrived in Tanzania. Once in Tanzania, I built rapport with *NGO-1* staff and participants and used purposive and snowball sampling to secure participants for interviews and sharing circles. Building rapport, as Streubert and Rinaldi Carpenter (2011) suggest, including ensuring confidentiality, assists to facilitate rich dialogue. The most effective strategy for recruitment was my partnership with NGO staff who provided access to key stakeholders and mothers involved in mamas' groups partially run by *NGO-1* in Dar es Salaam and Mwanza.

Description of the Sample

As asserted by Polit and Beck (2017), relatively small sample sizes in qualitative research can produce rich, substantive data. This is particularly evident when information provided by participants is rich in depth and story, "illuminating the patterns, categories, and dimensions of the phenomenon under study" (p. 497). As mentioned, this study's sample is part of a broader study which involves eight sharing circles and individual interviews (*N*= 62). For the primary

sample of this study, I drew on the narratives of six mothers. Another 12 mothers' experiences, suggestions, or reflections are included in a secondary sample. To further understand the context and services or resources available, I drew on interviews with six key stakeholders. Thus, the total sample for this thesis was 24 participants (*N*=24). Table 1 depicts key demographic details related to the entire sample, including presence of albinism, age range of participants, occupation or employment status, and religious affiliation. Figures 5, 6, and 7 illustrate the number of children with (*n*= 24, 33%) and without (*n* = 48, 67%) albinism represented, the marital status of mothers in this study, and the age range of children with and without albinism, respectively. These figures provide important context to better understand the complexities within the study sample.
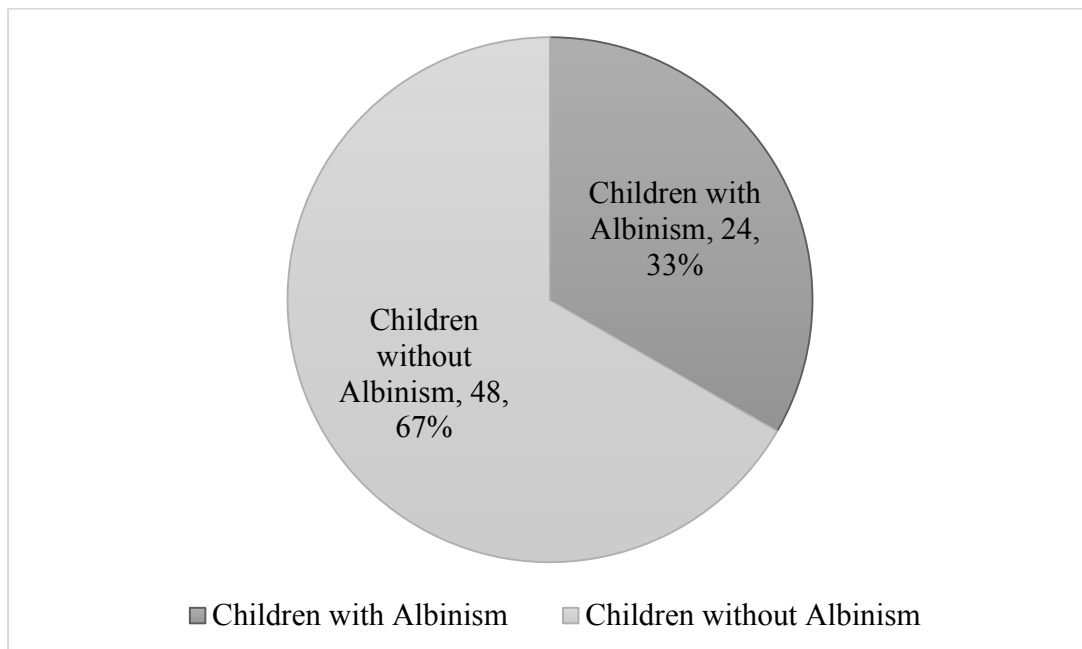
Figure 5. Number of children with and without albinism represented by mothers in this study.

Table 1

Demographics of Participant Sample

Demographic Characteristic	Mother (*n* = 18)	Key Stakeholder (*n* = 6)
Albinism		
Person with Albinism	3	1
Person without Albinism	15	5
Age Range of Participant		
21-30	3	2
31-40	7	2
41-50	5	1
51-60	2	0
61-70	1	1
Occupation		
NGO/CSO Staff	0	2
Teacher	1	1
Social Worker	0	1
Nurse/Midwife	0	2
Employment Status		
Collective Income (e.g., Mamas' Groups)	2	0
Subsistence Income (e.g., selling fruit, milling grain, sewing, soap making	1	0
Collective & Subsistence Income	13	0
Employment Income	1	6
Retired	1	0
Religious Affiliation		
Christian	8	4
Catholic	7	2
Muslim	3	0

Due to the nature of ethnographic research, all interviews, experiences in the field, and interactions with partner organizations speak to my understanding of the data collected and its analysis, highlighting key participant interviews and interactions that highlight and contextualize findings (Miles & Hubermas, 1994).
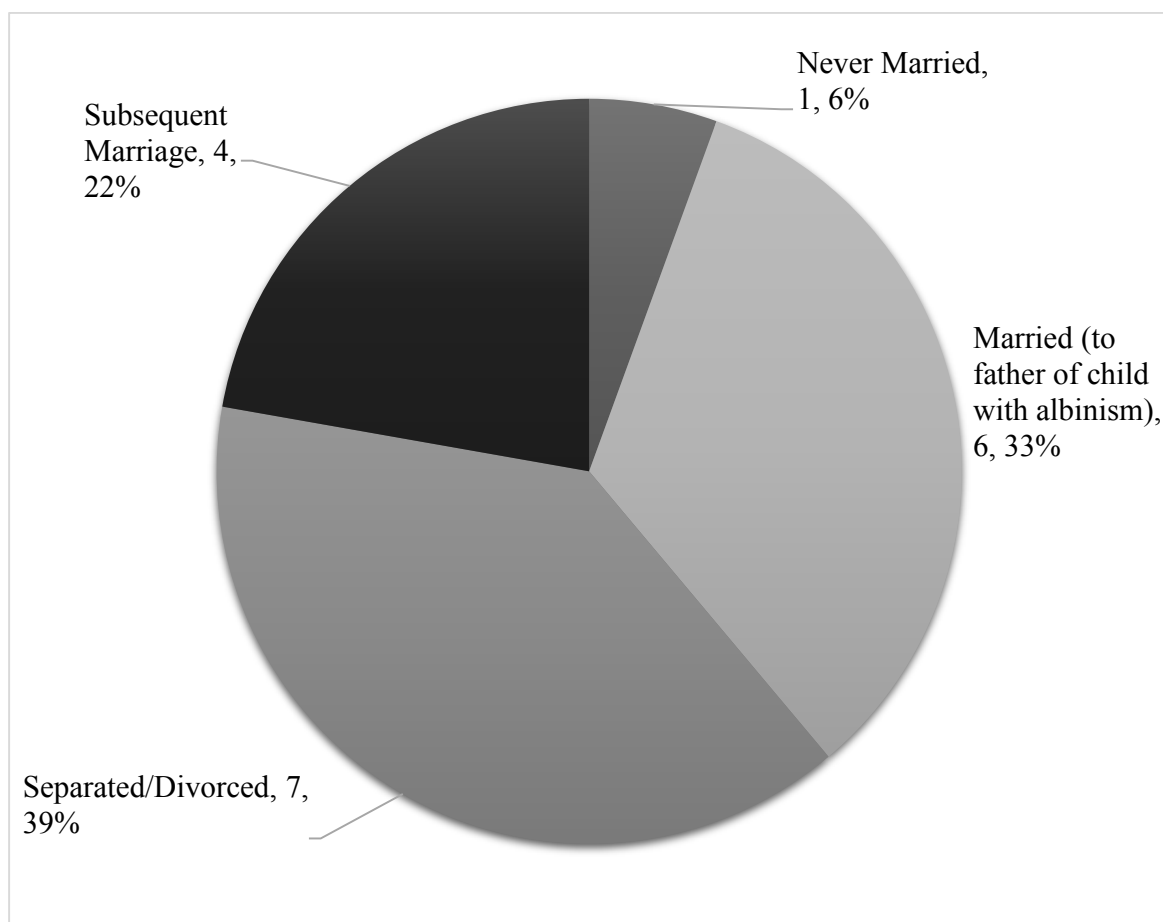
Figure 6. Marital status of mothers interviewed.
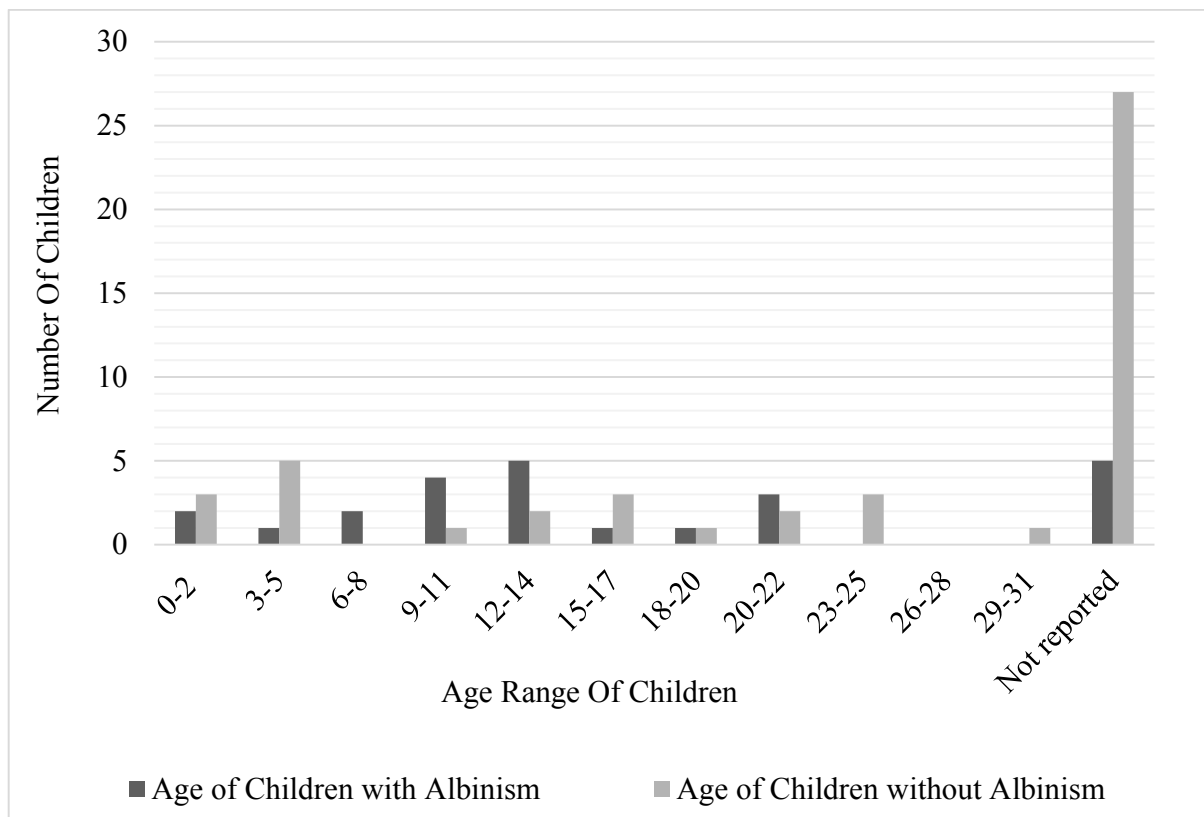
Figure 7. Ages of children with and without albinism represented by mothers in the study.

Data Analysis

Each interview was transcribed, verbatim, in English, by a hired transcriptionist. Data was and remains stored on my password-protected computer to ensure confidentiality and data integrity, as well as on TWU-approved cloud-based storage, ownCloud™, to allow secure sharing of data between myself and my committee. Once interviews were transcribed, they, along with the extensive field notes and reflexive journals, were uploaded into QSR International's NVivo™ 12 software that enabled coding of each interview as well as extensive review of my reflexive journals (see Appendix J for Study Data Codebook).

Data analysis consisted of two aspects: coding the transcripts to organize the data, and ethnographic writing to interpret the data. Madison (2005) describes coding as "the process of grouping together themes and categories that you have accumulated in the field" (p. 36). Using QSR International's NVivo™ 12 software, I created an initial codebook where I began to organize data collected into broad groupings. These groups included the following: vantage point of mothers, community responses, life stages, human rights, identified needs by mothers, ideas identified by partners, and research methodology. Streubert and Rinaldi Carpenter (2011) state that "ethnographic data analysis is a search for patterns. These patterns make up the culture" (p. 188). With the goal being immersion in the data, I spent an extended amount of time "in the data." This included prolonged time reviewing interview transcripts, listening to recordings of interviews, and reflecting on field notes and reflexive journals—coding all material throughout the process (Madison, 2005; Streubert & Rinaldi Carpenter, 2011).

To further ensure validity and reliability, Dr. Reimer-Kirkham reviewed my initial codebook in QSR International's NVivo™ 12, followed by a process of ongoing co-creation of the codebook, recognizing the iterative process of data analysis in ethnographic research. This was achieved through regular communication and meetings with my committee throughout fieldwork as well as during the months of data analysis that followed. Drs. Reimer-Kirkham and Astle, as thesis supervisors and with the understanding that "identifying key categories and themes is seldom a tidy, linear process," were both involved in ongoing discussions around inchoate findings (Polit & Beck, 2017, p. 536). Their expertise in the fields of qualitative research, critical theory, and global health were invaluable to the data analysis process.

The process of ethnographic writing for the purpose of data analysis is well noted in qualitative research literature (Miles & Hubermas, 1994; Streubert & Rinaldi Carpenter, 2011). The work of Clifford and Marcus (1986) calls for "ethnographers to see writing as a craft that involves culture, aesthetics, and politics" (as cited in Silverman & Marvasti, 2008, p. 443). This process invited an embodiment of the data as story, much like the oral story-telling tradition enshrined within Tanzanian culture. It was in this process of ethnographic writing and rewriting that, alongside Reimer-Kirkham, we realized that what was surfacing were rich storylines. As Atkinson (1991) asserts:

> The analytic induction of categories, themes and relationships; the explication of meaning; and the understanding of action may all proceed via the writing itself. … The "writing up" of the qualitative study is not merely a major and lengthy task; it is intrinsic to the "analysis," the "theory" and the "findings." (p. 164, as cited in Miles & Huberman, 1994, p. 299)

These rich storylines take the place of themes typical of other qualitative methods, and emerge in Chapter Five, following a case study of one participant in Chapter Four. The chosen case study highlights nearly every storyline identified through the coding and ethnographic writing process. Thus, the storylines in Chapter Five expand on key points identified in Chapter Four.

Scientific Quality and Credibility

To foster the rigour of this qualitative study, Lincoln and Guba's framework consisting of the following five "criteria for developing the *trustworthiness*" of qualitative research has been employed: credibility, dependability, confirmability, transferability, and authenticity (Polit & Beck, 2017, p. 559). While not without critique, frameworks and strategies such as Lincoln and

Guba's have been applied to enhance the rigour of qualitative studies to ensure "good qualitative work [that] is both descriptively sound and explicit and interpretively rich and innovative" (p. 559). Carspecken (1996), a critical ethnographer himself who has written extensively on critical theories and critical ethnography, supports Guba and Lincoln's framework for critical ethnographic studies.

Credibility has been achieved via the prolonged engagement and immersion in the field as well as by way of ongoing member checking and knowledge exchange with our partners in the field as well as with some of the mothers interviewed. With research partners in the field, this continues to occur virtually by way of email messages as well as conference calls. With participants, that occurred during the second field visit in October to November 2019. During fieldwork and throughout the data analysis phase, I was able to maintain communication with Waithera as the main cultural liaison, Ero, and other partners in Tanzania—all whom have familiarity with the Tanzanian context. In these ongoing consultations, we "deliberate[ly] prob[ed] to ensure that participants' meanings were understood" (Polit & Beck, 2017, p. 564).

Dependability, which "refers to the stability (reliability) of data over time" (p. 559), has been achieved using an audit trail to track ongoing decisions made in the research process and data and theoretical triangulation. Data triangulation, including space and person triangulation, is incorporated in this study. I conducted research in three separate places and with various "level(s) of person(s)" (Streubert & Rinaldi Carpenter, 2011, p. 353): Geneva, Switzerland during a roundtable conference on human rights and albinism with a key stakeholders; and the Dar es Salaam and Mwanza regions with mothers of children with albinism and key stakeholders. Theoretical triangulation is employed by way of applying "more than one lens or

theory in the analysis of the same data set" (p. 358). Because data analysis occurred using Africana Womanism (Hudson-Weems, 2019) and a human rights lens, I was "more likely to gain a complete or holistic understanding" of emerging storylines (p. 358).

Confirmability, particularly as I collaborated closely with Waithera, who was also the primary interpreter, throughout my fieldwork, was achieved through review of data, findings, and ongoing dialogue with Waithera during my time in Tanzania to ensure "findings…reflect the participant's voices and the conditions of the inquiry" and not my own "biases or perspectives" (Polit & Beck, 2017, p. 560). Transferability has been sought within the context of the mothering experience of women with children who have albinism within the sub-Saharan African context— acknowledging that while some findings may transfer to other regions, Africa is a continent with varied culture and socio-political conditions. Finally, using verbatim quotes, rich description from field notes, and photos of the everyday lives of these women and their children, authenticity remains an ultimate goal. Polit and Beck (2017) assert that "authenticity emerges in a report when it conveys the feeling tone of participant's lives as they are lived" (p. 560). I have sought to honour the voices and narratives of the women in this study ensuring they are central to each phase of analysis and writing by attending to my own positioning, values, worldview, and assumptions through consistent reflexivity (e.g., reflexive journals, dialogue with liaison, regular debriefing meetings with thesis supervisors), discussed in the following section.

Researcher Reflexivity and Positionality

This focus on social change requires that I as the researcher acknowledge my own positionality; that is, I acknowledge my "own power, privilege, and biases just as [I] am denouncing the power structures that surround" the topic at hand (Madison, 2005, p. 7). This

acknowledgement becomes an active practice, particularly when engaging in fieldwork, through what is described as reflexivity, where I as the researcher embrace the "need to have an ongoing conversation about the experience while simultaneously living the moment"—reflecting on how my own "values and views may influence findings" (Jootun, McGhee, & Marland, 2009, p. 42; Streubert & Rinaldi Carpenter, 2011, p. 174). Jootun et al. (2009) argue that reflective practices throughout qualitative research studies enhance a study's credibility. Primeau (2003) furthers the concept of reflexivity in her assertion that it "enhances the quality of research through its ability to extend our understanding of how our positions and interest as researchers affect all stages of the research process" (p. 9). This reflexivity was accomplished by way of extensive fieldnotes and guided reflexive journals (see Appendix I) throughout the study, particularly during fieldwork in Tanzania. This reflective approach introduced the concept of interpretive reflexivity (Lichterman, 2017). Lichterman (2017) asserts that "in a more interpretive practice of reflexivity, ethnographers explore how they figured out other people's meanings in the field, instead of focusing on correlations between their claims and their social position" (p. 35). With a tendency to get "bogged down" with the tensions of my position as a privileged, white, North American woman in Tanzania, this concept of interpretive reflexivity lent to this study a transparency that, hopefully, illuminates for the reader my process in drawing the conclusions that I do. Through many statements from Waithera, "No, you aren't understanding," to participants providing me with pat answers they perceived I wanted to hear, such as "*NGO-1 is very good and I am so grateful*," the way I had to navigate unearthing the reality of what I was hearing and seeing required a willingness to not know, to be wrong, to feel uncomfortable, and to keep asking questions until Waithera, participants, and stakeholders would decisively affirm, "Yes!"

Limitations

As Streubert and Rinaldi Carpenter (2011) contend, while ethnographic researchers become, in part, a part of the "cultural scene, [we] will never fully have the insider's (emic) view" (p. 172). This is particularly true, the authors assert, for new researchers (Streubert & Rinaldi Carpenter, 2011). While this does represent a significant limitation, safeguards are in place to decrease their impact: consistent dialogue with Waithera, herself a Kenyan woman with albinism; access to conversation with the UN Independent Expert on the enjoyment of human rights by persons with albinism, Ero; and access to consult with *NGO-1* support staff to ensure that my etic view, as an outsider interpreting what I am observing with all five senses, is as accurate as possible. Very affirming to this process was the knowledge exchange meeting conducted during the second field visit alongside my thesis supervisors, Drs. Reimer-Kirkham and Astle, in which analysis to that point was confirmed and further support added with contextualization.

Additional limitations include the relatively short length of time for ethnographic fieldwork and the fact that I as the researcher do not speak Kiswahili. True critical ethnography provides ample time and opportunity for the researcher to become embedded within the culture, living amongst the local people and, potentially, returning several times to the same location for clarification and further study (Madison, 2005). By explicitly labeling this study as "focused," I am introducing the study as specific to one aspect of the larger project. Regarding the language barrier, Waithera provided not only language service, but also the unique addition of cultural translation as well thus increasing therapeutic rapport between myself and the mothers that chose to participate in this study. Because we traveled together and debriefed following each event, I

had the ongoing opportunity to ensure that I correctly (as much as possible from my outsider position) understood what was being said (and not said) during interviews, sharing circles, and within participant observations.

In terms of representativeness of the sample, this study is limited in that most mothers interviewed (except for one) were connected in some way or another to an NGO. As a result, the stories gathered reflect the move from deprivation to resourced rather than providing counter stories of women with and without resources. Future research should be conducted in such a way that ensures a broad "spread" of participants in terms of access to and engaging in resources from NGOs or government outlets. However, the rich description of women describing their lives and experiences pre-NGO intervention to post-NGO intervention is remarkable—pointing to the existence of such counter stories and what they may entail throughout their lifespan.

Ethical Considerations

Ethical approval for this study was obtained from Trinity Western University Research Ethics Board (REB) as well as through the Tanzania Commission for Science and Technology (COSTECH) and the National Institute for Medical Research (NIMR) in Tanzania (see Appendices K, L, and M for research permits). Potential participants from mamas' groups in Dar es Salaam and Mwanza regions were informed about the study by NGO partners prior to my arrival. Recruitment of key stakeholders also began with NGO partners and Waithera prior to and throughout fieldwork.

Following a verbal explanation of the study's intent, a review of the interview process, and ensuring participants were aware of their ability to withdraw from the research at any point (up until thesis defense in Spring 2020), participants were requested to sign a consent form.

Forms were in both English and Kiswahili (see Appendices N and O for informed consent

forms). Because some research participants did not read or write, the process of assent was used

as needed. Verbal consent was achieved with the "affirmative agreement to participate" in the

study, following verbal explanation in their own language in place of the signed consent form

(Polit & Beck, 2017, p. 720). As recommended by Streubert and Rinaldi Carpenter (2011),

process-informed consent was utilized, allowing for ongoing renegotiation of participation. Polit

and Beck (2017) assert that process consent "allow[s] participants to play a collaborative role in

making decisions about ongoing participation" (p. 144). Given the nature of this study and the

focus on the gendered nature of albinism—acknowledging the various human rights threats

experienced by persons with albinism—emphasis on empowerment, choice, and space to voice

their lived experiences while determining ongoing participation in the aim of this study was

deemed of critical importance (Madison, 2005; Shimmin et al., 2017; Varcoe, Browne, &

Cender, 2014). Further, because of the potential for unearthing painful, traumatic experiences

throughout an interview or focus group discussion (Shimmin et al., 2017) and my responsibility

as the researcher to "protect the welfare of the participants" (Streubert & Rinaldi Carpenter,

2011, p. 61), *NGO-1* staff with qualifications to debrief with participants were identified and

available for follow-up after interviews. Additionally, as a nurse trained in trauma-informed

practice, I consistently assessed participants for signs of trauma and distress, offering to end the

interview and noting when to conclude discussions and transition the topic. During these

situations, Waithera and I consulted on next steps. Of note, while some participants relaying

traumatic experiences teared up or cried, each expressed a desire to continue the interview, citing

"so that no other woman has to go through what I went through." At the end of each interview or

sharing circle, Waithera and I debriefed the interview with participants ensuring they were aware of resources available to them should they want or need to discuss further what came up in the interview (see Appendices P and Q for debrief forms).

Following interviews with many of the mothers, it was clear to me and my committee that there were instances where safety and well-being were at a more immediate risk. In these instances, mothers had explicitly requested help from researchers to advocate on their behalf. As the original REB did not specify that I would bring to the attention of partner organizations particular cases where their intervention was needed, we submitted a request for amendment. With REB approval granted and as part of a larger memo reporting on the research fieldwork submitted to our partner organization, we presented five particular cases in which their intervention could result in ensuring the protection of the family's human rights and well-being. Each of these cases was attended to by the organization, which was very receptive and open to feedback.

Confidentiality and anonymity have been maintained throughout data collection, analysis, and in the final report by using pseudonyms, ensuring not to use any key identifiers that could give away a participant's, or their family member's, true identity. Further, transcripts and the original recorded interviews, aside from the transcriptionist who signed a confidentiality agreement, were only reviewed by myself and my committee—otherwise these documents and recordings remain on the password-protected cloud-based storage ownCloud^{TM}. Particularly due to the human rights threats and violations that this community experiences, the researcher recognizes that participant's information must be kept completely confidential to ensure safety. While risk exists in terms of potential for triggering a traumatic experience during interviews or

sharing circles, the benefit lies in the potential for this process to be a "loudspeaker" amplifying the lived experiences, perspectives, and opinions of women regarding how the national and global community could best support them and their children with albinism.

Transportation costs were covered for mothers to and from interview locations. When interviewed outside of their homes, meals were also provided. When interviews took place in participant homes, gifts of sugar, tea, and water were presented to participants. A meal or refreshments were provided for key stakeholders when interviewed outside of their home. The cultural liaison received payment for her work. Her airfare, lodging, and meals were also covered. Gifts in the form of tea towels, university pens, and Canadian pins for each NGO partner and involved staff were presented.

Chapter Summary

In this chapter, I have detailed the research design and methodology, scientific quality and credibility, and ethical considerations accounted for. The intersectional experience of women who mother children with albinism in Tanzania represents a missing piece in the movement towards promoting the enjoyment of human rights of persons with albinism and that of their families. By using a focused critical ethnographic methodology alongside Hudson-Weems' (2019) Africana Womanism, trauma-informed research methods, and a human rights lens, this study seeks to centralize the voices and narratives of mothers impacted by albinism. In the following chapter (Chapter Four), I will begin presenting the findings of this focused critical ethnography through the narrative of Imara, one participant whose journey provides a key case study.

Figure 8. A mother roasts peanuts in one of the Wamama Wanaojali workshops in preparation

for a market.

Chapter Four: The Case Study

In this chapter and the next, I present the findings of this focused critical ethnography. Written in an ethnographic style to bring to life the lived experiences of mothering children with albinism in Tanzania, Chapter Four contains an account of one participant's story, Imara, as told to us in a sharing circle and individual interview. Imara's journey of delivering and raising daughters with albinism provides a framework for understanding the rest of the stories told to us by participants and serves as a case study. Imara's story is complex with intersectional factors influencing how she and her daughters navigate everyday life, experience health and wellness, and experience access or threats to their human rights. To attempt to capture elements of a woman's experience as a mother of children with albinism, I use Imara's story as the scaffolding to this critical ethnography, subsequently layering in the experiences of other women (participants) whose experiences offer either a counter perspective or reflect Imara's experience, thus corroborating the lived experience of mothers impacted by albinism. In Chapter Five, I follow the key storylines revealed in Imara's case and illustrate in a thematic style how they reflect the everyday lives of the other mothers in this study.

The Case Study of Imara

We are in the back of Sarah's[3] Land Cruiser bouncing down the dirt road towards *NGO-2*'s headquarters where the *Wamama Wanaojali* ("Caring Mothers" in Kiswahili) group in Mwanza gathers. The security guard at the compound gate clearly knows Sarah well—they greet

[3] Sarah facilitates the mamas' group in Mwanza. This is a group of mothers impacted by albinism, either as mothers of children with albinism or mothers with albinism themselves. Further details are provided in this chapter as well as in Chapter Five.

each other with broad smiles and greetings in Kiswahili. Sarah introduces Waithera and me. We are warmly welcomed inside the compound—the extension of trust and hospitality by virtue of our contact's established relationship. At the bottom of the driveway, we reach what used to serve as a garage. About ten women are inside, making a variety of goods: roasted peanuts, beeswax wraps (these replace saran wrap; apparently, expatriates love to purchase this item), soaps, and beeswax candles. The group is preparing for a market in the coming week in which they hope to sell a large quantity of their products. For many of these mothers, this group serves as a vital source of social support, but also provides a key source of income. Sarah tells us that she has witnessed the self-esteem and confidence in each of these women grow as a result of making, marketing, and successfully selling their handmade products. As we drive up to their workshop, we interrupt their banter and laughter as they all navigate the small space, almost chaotic as they tend to various tasks and sooth crying infants.

Most of the mothers immediately recognize Waithera—they embrace her, welcoming her back. Waithera worked with *NGO-1* about five years ago and helped to form these groups, recognizing that mothers might benefit from the support of shared experience: All of these women either have children with albinism or have albinism themselves. Sarah and Waithera introduce me to each woman. Welcoming hugs and handshakes follow. Waithera builds the enthusiasm for the purpose of our visit reminding them of the importance of their shared experience as women impacted by albinism and the power to create change through sharing their lived experiences.

Imara was sitting down, leaning over a massive pot on a propane flame stirring several pounds of roasted peanuts. She appeared focused and determined. Sarah organized everyone into

a circle where we introduced ourselves and eventually formed two groups with a plan of

engaging in a sharing circle with one of the groups that day. Imara joined the group outside and

we listened as each woman shared parts of her story, responding to a question that engaged with

her story in some way. As Waithera and I held space for the stories to unfold, we realized

quickly that this was the first time they were hearing the deeper layers of each other's stories.

There were sighs, tears, and subtle movements to comfort each other. We were bearing witness

to friendship deepening and broadening as they learned the complexities of their sister's stories.

Imara's story captures so many of these complexities—layers of lived experience as a woman

with six children, three of whom have albinism.

Imara begins by telling us that she delivered her first daughter, Aisha, when she was just

14 years old. Waithera relayed to me that Imara,

> [R]ecalls when she got the baby she could hear the undertones from the nurses, "Oh,
>
> she's given birth to an albino." And because her mother-in-law and step sister were
>
> outside, the nurses called them and told them, "Oh, just in case you think we've
>
> exchanged your baby, the baby, here is what she has delivered." And like for her she was
>
> just grateful because that is what came out of her womb. (Imara, Sharing Circle-3)

Imara went on to explain that her husband's first question was, "What is this you have delivered?

Did you sleep with an albino?" Accused of having an affair, her husband took no interest in their

daughter. As was true in other participants' stories, an older woman on her husband's side of the

family met Imara's daughter and said, "this child is my sister," introducing the concept of

albinism as genetic and passed through a bloodline. Once this elder in the family embraced

Aisha, Imara's mother-in-law "started being friendly and loving" towards them both. Her

husband's mentality, however, did not change. He refused to acknowledge Aisha as his own, much less provide for her or take care of her. At school age, Imara implored him to provide financial support so that Aisha could attend school. He took no interest: Imara was left solely responsible for Aisha. To pay for school fees, Imara sold bananas and mangoes, gathering them herself and selling them while Aisha was in school.

When Aisha was six years old, Imara became pregnant with their second child. Worried that she would deliver another child with albinism, the husband left her and did not return until the baby, who did not have albinism, was "sitting up." Upon his return home, the support and care he provided was directed only towards his second daughter without albinism—he paid no attention to Aisha. Imara talked about this motivating her even more to continue to work and provide for Aisha as she continued selling fruit that she gathered on her own. Soon Imara delivered their third child: another daughter with albinism. Within two weeks of delivery, her husband beat her severely—accusing her "of cheating with that albino man up to now." Compounding her husband's anger was the fact that Imara not only delivered babies with albinism, but also had only delivered girls. Her husband, determined to find a woman who would give him a son and one without albinism, left Imara with the three children.

At this point in the interview, Imara could no longer hold back her tears. Her friends in the circle leaned in, the all-knowing sighs mixed with some acknowledging that they had no idea how bad this part of her story actually was. Waithera and I could no longer hold back our tears either. Here is a woman, fighting for her place in her home, her community, and her society simply because she and *this* husband continue to pass down the albinism gene that they *both* possess: "I knew from deep within that this is my child and his child, I did not know what to do."

Imara decided to stay with her husband. She speaks to this decision as a choice based not only on her desire to protect her children and ensure their well-being, but also acknowledging, "even if I move out, where would I move out to? Like there's nobody else who's going to marry a lady like two kids with, three kids and two have albinism. I'll be causing more trauma and more stress to my children because when they ask about their father what will I tell them?"

Some years later, Imara became pregnant with their fourth child: their third daughter with albinism. Her husband's response now was to "get myself another wife who can give me boys and who can also not deliver children with albinism." Still, Imara resolved not to leave this man and the little support she received by doing so (e.g., keeping her home, help with the daughter who does not have albinism). Imara stated in the sharing circle that "even if they live there she's single handedly raising her kids. So it's like she's married and not married at the same time." Articulating the experience of so many women in her position, Imara poignantly stated: "we live for today and not sure of tomorrow."

In terms of outside support, Imara's eldest daughter with albinism, Aisha, is the only one of her children that received NGO support. *NGO-1* sponsored her to attend a boarding school and then on to a vocational school to learn a trade after graduating secondary school. While Imara felt that this support reduced the financial burden she experienced, it also created a painful dynamic between the siblings. Her younger daughters watched Aisha get regular bottles of free sunscreen, scheduled and routine skin cancer screening and vision care, and, most of all, attend a quality boarding school where all of her basic needs were beyond met. These daughters attended day school in their home community, walking to and from each day. Following a security threat, however, in which a man was found loitering near their home, waiting for them to return from

school while Imara was working selling the fruit she had gathered for the day, Imara could no

longer leave her daughters for fear of their direct safety. Fortunately, this man requested

information from three of Imara's neighbors, all women. These women recognized this man as a

threat and strategically occupied his time while one of them went to find the Street Leader who

literally "blew the whistle" for other neighbors to come help. They attempted to detain this man,

but he ran away on foot. Fearing for the safety of her children, Imara knew she could no longer

work outside of her home if it meant ever leaving her daughters behind. A period of extreme lack

followed as Imara was unable to work. She had no way to feed her family anything more than

maize flour. This led her to approach the boarding school that Aisha was attending via

sponsorship: Lake Victoria Boarding School. After some time, the owner agreed, "if you

commit…you will always make sure you bring $50 in a month to at least offset the school fees

then I'll take in the kids." Imara worked hard to send her other two daughters with albinism to

the same boarding school that Aisha was originally attending. With her daughters now safe in a

boarding school setting, Imara was again able to work gathering and selling fruit, *mandazis* (fried

bread), as well as earning a marginal income from the mamas' group selling the crafts they make

collectively.

Beyond the stress of raising her daughters essentially on her own, Imara was diagnosed

with chronic diseases that require maintenance medications. In her words, this stress "is actually

the route to my [chronic illnesses]." Compounding the stress of her everyday life is now the cost

of medication, which she estimated to be 85,000 TSH (approximately $40 USD) monthly.

Between these costs, she notes that she is in significant debt to the boarding school (3.5 million

TSH or approximately $1500 USD). This debt threatens the safety and education of her younger

two daughters with albinism. Through tears, she told us that she was now having to make an impossible choice between school fees or purchasing her own medications. Purchasing the medication she needs would mean sending her girls back to the day school where their safety is compromised. Attempting to pay school fees at the boarding school, however, means foregoing her own medical treatment, risking major future complications. Untreated chronic diseases over years are detrimental to health, well-being, quality of life, as well as longevity. Her children desperately need Imara, and more than anyone else, she is acutely aware of this need. Imara acknowledged that the day schools are no safer than they were when she pulled her girls from them initially and put them in the boarding school. "But now money, the more I think about the financial burden the more I don't know how I'll offset myself from it…no it's not safe but I don't have a choice."

Aisha was originally going to a government day school (neighborhood school). At this school, she was experiencing a lot of discrimination and bullying from other students as well as from teachers and staff of the school. This was obviously distressing to Aisha as well as Imara, who felt limited in the effectiveness of her own advocacy as her mother. One of Aisha's teachers at this school approached Imara and told her about a school for the blind nearby "that has kids like [Aisha]." Such schools are generally government funded and have been used as alternatives for children with albinism. The education in these schools is geared towards the needs of children who are legally blind, teaching braille, not for students with low vision who, when provided with proper devices/options (e.g., monocles, glasses, seats at the front and centre of the classroom, large print books/exams), can read and write just fine. However, given the discrimination that Aisha was facing at school, Imara decided to send her to this school for the

blind. Once there, she visited her regularly. This was before she had more children. It is at this

school that *NGO-1* found Aisha and sponsored her.

At this point of sponsorship, their journey shifts, in many ways positively. However,

concern exists around involvement of parents. Imara notes that she received a call from the

school for the blind when Aisha was very young (about 7 years old):

> [T]elling me, "Ah, your kid got scholarship and she is, she has already left here and they
>
> are in schools in Mwanza." I was given a list of schools where she could be. And I started
>
> going to those schools, school by school looking for her, [several schools later] when I
>
> went to [name of school] I found her there and asked the daughter, and the daughter
>
> [Aisha] told me they got a sponsor and it is the sponsor who brought them from
>
> Misungwi to the school. So, when I asked the school now the school told me, "Yes, the
>
> sponsor brought them here."

Once Imara found her, she visited her at the new boarding school monthly. She mentioned her

surprise regarding sponsorship, but her relief that she would be safe and receive an excellent

education was more pronounced:

> She learned about the sponsor…a white man…after one year…So now, like for her, she
>
> was happy. First because, initially her child was in a mainstream school but the
>
> environment was not very good. But now this year she is in another better school and she
>
> was very sure in that school she would do better than she would have done in that special
>
> school.

In addition to feeling hopeful about Aisha's opportunity as a grantee of this NGO, Imara

experienced challenges visiting and maintaining regular access to her now that she had moved

schools and was recognized as a sponsored child of *NGO-1*. She describes the various barriers to visiting Aisha or to having her home for holiday breaks:

> Imara: She only knew a sponsor…a white man from Canada is sponsoring kids…For her she was happy. First because, initially, her child was in a mainstream school but the environment was not very good. Now she is in another better school and she was very sure she would do better than she would have done in a special school [e.g., school for the blind]. But now she says the only problem was every time they would close school she had to go through the process of getting a letter from the district leader to take her own child home and that was something that she had to do every time they closed. You understand?
>
> Researcher: What do you think of that process? What was that like for you?
>
> Imara: She asked herself very many questions. Like, how now all of a sudden my child, I have to continue justifying that I am the parent? I have to come, have the local leader write a letter and I take the letter to the district officer to prove that it is my child. I have to keep reminding… every time I'm justifying "this is my child." It feels like the power of being the parent to that child is not there anymore. She says, "you see that process you know it is expensive…You really needed to make sacrifices and plan ahead of time, to bring your own child home." And when she was in the other school that process was not there…because she was in charge of the child [as she had placed her there herself].

While she expressed feeling positive, thankful, and even reliant on sponsorships for her child(ren) with albinism to obtain excellent and safe education, there was grief in the separation

from Aisha as articulated in Imara's words, "It feels like the power of being the parent to that child is not there anymore."

Despite this loss of power and the grief associated, Imara's story illustrates how poverty, perpetuating a chronic lack of choice/options, requires continued engagement with sponsorship models and, further, a willingness to ask for further assistance, an experience that is both humbling and sacrificial as it may result in her child going away to a boarding school. She desperately wants her children with albinism to be safe, have access to excellent education, and experience equal access to health services (e.g., sunscreen, dermatologist skin screening), so "she says she once approached [the organization staff] and told them about [her other] children with albinism and they said, 'no, we are not giving any more scholarships.' This was in 2013." For Imara, reaching out for assistance took courage, humility, and a willingness to face refusal. Hopeful that her other children with albinism would receive access to what their eldest sister had as a grantee of an NGO, that is ensuring her education and health needs are attended to, she took a bold step and asked for what she needed. After she told us about being informed that there were no more scholarships available, the natural next question was how she managed raising all of her kids within this context.

> Researcher: So, how did you manage…trying to parent Aisha and these other two that were at home?
>
> Imara: So it was really hard, of course, but now even if they didn't get scholarships they were my kids and that's how I explained to you how I had to start doing business to try to put them in school. Yes.

Imara's resolve as mother and primary caregiver to her two other daughters with albinism was visceral in this interview—she reached out where she saw the opportunity, but her grit did not wane when help was not available to her. She kept going, continuing to creatively navigate her family's survival. The business she is referring to is selling mangoes, bananas, and *mandazi*.

This discussion further highlighted how access to health resources such as sunscreen appears to be directly associated with proximity to NGO/CSO services. When all three of her children were attending Lake Victoria Boarding School (Aisha NGO-sponsored and Imara funding the younger two), all three had some access to what the NGOs would bring for their grantees. The two children attending without sponsorship were dependent on what Waithera (CL) translated as "spillage" from those who had the sunscreen. Anything left over, her other daughters would share and use.

This conversation naturally progressed to Imara describing how parenting differed between Aisha and her other children.

Imara/Waithera: So she says, you know, if you remember when I told you some of the biggest contributing factors is looking at my kids and feeling they are a bit unequal. Even my [chronic disease is impacted] most days when I think about some of these things…

Researcher: What are those things?

Imara/Waithera: She says you know even the thought of my children, my child, there's no sunscreen. Like a simple thought like that already…because, see for me, I have to start stressing where to get sunscreen before they realize they don't have any and their sister has. And sometimes she would call [the TAS representative] to find out if he has or doesn't have, and if he doesn't have they have to apply no sunscreen and the sister has

sunscreen…See now from when they went to Lake Victoria Boarding School

…sunscreen…was not a priority in my thoughts then because they would get this spillage

from others. But then even when they are there, I have to think, I don't have to worry

about Aisha but I have to worry about school feels for the others.

Researcher: I'm curious, too, just between her kids with albinism and her two without,

are there any differences in how she parents? Or parenting strategies.

Imara/Waithera: So you see, all her kids are equal in her eyes. Even when they don't have

sunscreen they will apply any other lotion that the others are applying. And then she now

has to ensure they don't go out in the sun. So, it's expensive of course to keep up with the

children with albinism but it is also manageable. Cause then when they don't [have

sunscreen they don't] go to the bright light and all of that.

This part of Imara's story illustrates the focus around protecting her children from life-

threatening UV rays. The central worry is practical: How will she ensure they have what they

need to prevent skin cancer? Clearly a difference exists between how her sponsored daughter

receives these resources versus how her two un-sponsored daughters access them. She is

highlighting the inequities that exist between her own children.

Part of my research objective is to determine the gendered natures of parenting in the

presence of albinism: how mothering differs from the fathering experience. Exploring this with

Imara illustrated the inequities that exist between spouses/partners. Her response illustrates the

centrality of women and mothers in the narrative around albinism:

Researcher: …how are the challenges different for a woman who has children with

albinism versus for the man?

Imara: The mother gets challenges of course because the first thing he'll do is to abandon

you and the children.

Researcher: And his abandonment, what are the reasons behind that for a man?

Imara: For me, it's because the kids have albinism and [all of our] kids are girls.

Her blunt response struck me—it was so matter-of-fact, an "obviously!"

To conclude our interviews with mothers, we always asked if they had any

recommendations and what resources they would like to see. We ended our interview with Imara

this way, too. She responded with the following:

Imara/Waithera: She says, for me, I think if my children got quality education then that's

the biggest investment that can be done for me. But also for me, my health, the less

thought I have to worry about these children then I will be able to be more productive to

raise the household. So, basically, her health and the education of her children. Those are

like her key priorities right now because she says like the issue of security it is easy to

deal with the security issue when these others are taken care of.

This response was followed with a raw and vulnerable disclosure of how overwhelmed she

currently is. As I thanked her for her time and the interview, tears fell from her eyes and

Waithera sat closer, wrapping her arm around her. As they spoke in Kiswahili, I stood up from

my chair and sat next to Imara, my hand on her shoulder unable to stop my own tears. They

spoke in Kiswahili for a few moments until Waithera translated the following:

Imara/Waithera: So she's saying, we have to bring you on board. No, she's saying you

know raising all these kids alone as a woman, it's the hardest thing and it's not easy. And

she's telling me to imagine it, now the daughter that is in form four, even after form four

it's not like it's the end of her needing money to go on cause she has to go on to like advanced level, you see? And that also needs money. So, ya. That is really the reason why she can't stop thinking.

Reflexive Notes

As my own tears fell at the end of this interview, I understood that this kind of processing is privileged space. When you are working for survival in your everyday, what does it mean to take space to share experiences and their shadow stories? What does it mean *to be asked*, *to be sought after*, *and to be heard?* This was the goal at the heart of this ethnographic study: to bear witness to the lived experiences of mothers and to hear and record their stories for a broad, responsible audience. The intention is that Imara's story and those of her fellow sisters in this study motivate those in positions of authority and influence to chart a path forward alongside families impacted by albinism.

Considering Imara's story as a narrative, illustrating the experience of a woman from the moment she delivers her first child with albinism, the immediate postpartum moments are clearly pivotal. Upon delivery, Imara's first responsibility as a mother is to explain how this child came to be, how she has delivered a child whose skin is so different than hers, than her partner's. The onus is on her to explain, to define, to defend, to protect. She is the one that has carried the child for nine months, it is her womb that protects and forms their children. It is her body that delivers such children. Further, for Imara's, it is her body which delivers girls. The compounding burdens that women who deliver a child with albinism bear present themselves from the moment the babe emerges with their white head in the birth canal. The difference is immediate. The questions are immediate. The blame is immediate. The transgression she stands accused of is completely

outside of Imara's control: the judgement and penalty delivered by her spouse, family,

community, and then by broader society. Witnessing within this sharing circle, the level of

shared experience, the all-knowing despite not knowing the particulars of each other's stories—

the shared understanding of their lived experiences: Yes, this is what it has meant to be a mother

impacted by albinism. The choice to embrace this baby, deemed other and wrong by a society

unsure how to explain such difference, is a radical decision itself. It is a resilient decision. To

utter "this is my baby," to stake that claim pushing against society's beliefs and norms, is to

accept ostracism, discrimination, isolation, and the potential of public shaming. This is an act of

radical resistance. As articulated in a later sharing circle on Ukerewe Island, "if parents do not

accept their child, it perpetuate[s] discrimination and teaches the community how to

discriminate/treat their child."

The moment in Imara's story where she described choosing to stay with her partner,

instead of leaving their home, highlights the concept of (non)choices that these mothers face. The

word *choice* is misleading. For a woman facing poverty in Tanzania, survival appears to be the

choice. What does it mean to survive as a single, divorced woman who chose to leave her

spouse, who has daughters with albinism, and who is daily grappling with the realities of

poverty? Any support that her spouse is willing to provide makes a substantial difference in her

economic and social position. To walk away from this support could affect the well-being of her

children, something Imara is not willing to risk. However, her own health and safety remain at

risk at the hands of a violent husband. The concern around fathers abandoning their children and

rejecting their partners or wives, even denying paternity, is far too common. Chapter Five will

explore this theme in more depth, but suffice to say, Imara acknowledged the challenge and pain

of raising her daughters alone and feeling the deep rejection and failure as a wife from her husband. Imara, however, never wavered in her commitment as a mother to her children, instead persevering in the uphill battle of advocating for her children whenever required or potentially beneficial.

For mothers who parent alone due to a partner or spouse unwilling to accept their child(ren) with albinism, support is either nonexistent or arrives eventually and in unsuspecting places. All of the women interviewed in the broader study ($n = 26$) noted finding such support by way of a single relative, a neighbor(s), a new partner, or a mamas' group where other women are in similar positions. These sources of support were sometimes the only thing preventing an attack or kidnapping of their child(ren) with albinism. Imara's example of neighbor women taking note of the suspicious man looking for her daughters with albinism amplifies the role that neighbors, particularly fellow women, play in each other's lives: The bond of motherhood remains despite difference. This example is a powerful representation of sisterhood.

Imara's decision-making process around how to prioritize conflicting needs in her home is again representative of the various (non)choices that mothers confront. She faces the impossible decision of purchasing medications to manage her own chronic illnesses ensuring her ability to be present to parent or sending her children to boarding school to ensure their safety. She cannot have both. From a medical perspective, we know that stress and anxiety directly affect many chronic conditions. What Imara described is the persistent feedback loop referenced by so many of the women whom we spoke to: managing their own health and well-being and that of their children without albinism, all while desperately navigating methods to try and keep their children with albinism safe. For the large majority of women impacted by albinism, this

journey is solo. Is it even reasonable to conceptualize Imara's layered, intersectional options as choices?

In terms of sponsorship, Imara's story is representative of a concerning theme that was discussed with other mothers and key informants: loss of control in the parenting dynamic. These undertones of loss of power, control, parenting, and relationship with Aisha were expressed simultaneously alongside gratitude and a request for further sponsorship of her other children with albinism. As a woman experiencing little choice in her everyday life due to social constructions of gender, lack of resources, stigma and isolation, agency in parenting becomes vital to respect.

Access to health services and related resources continues to be a source of anxiety for mothers like Imara. Her clearly articulated worry and concern is practical in nature and highlighted the very real lack of sufficient access to resources: access to steady supplies of sunscreen (particularly when your child is not sponsored), access to regular assessments by dermatologists and eye specialists, and access to finances that would relieve most of these everyday concerns. When worry around accessing resources requires most of their energy, little is remaining for the countless other complexities involved in mothering. When resources are slim or provided only to children sponsored, inequities between and within families impacted widen. This is where the importance of government and NGO partnerships are vital to shifting the narrative and experience for these families. With their dependence on philanthropic donors, NGOs cannot bear the full burden indefinitely. Mothers know what they need. As mentioned, we asked mothers this very thing at the end of each interview. Most often, their response was a

request for capital to invest in business models that would provide them the ability to earn a

steady income as, by and large, they remain the sole breadwinners for their families.

Chapter Summary

This chapter has provided a "first window" or understanding into the findings of this

study, with the narrative of Imara, a mother impacted by albinism. Imara's narrative becomes the

platform for the storylines featured in the next chapter (Five). Drawing on data from other

participants to explicate how experiences throughout from delivery to young adulthood differ or

echo Imara's story, the aim is to offer a fulsome assessment of how mothers interviewed

experience having and raising children with albinism in their Tanzanian context.

Figure 9. Mothers walking with Waithera and I to a sharing circle.

Chapter Five: Expansion of Key Storylines

In this second findings chapter, I place Imara's story in the context of data from other mothers of children with albinism, as well as key informants. This analytic contextualization is critical to understanding the unique storylines of the mothering experience of women who have children with albinism in Tanzania. By storylines, I am referring to the main points in the arc of experience for mothers impacted by albinism. Each storyline is comprised of subplots. In line with the aims of critical ethnography, ethnographic writing "encourages the advancement of social justice through research" (Silverman & Marvasti, 2008, p. 446), tending to silences, injustice, and human suffering (Madison, 2005). Storylines are central to engaging the spectrum of experiences voiced by mothers in this study, expanding upon Imara's narrative. Within this chapter, I present and expand upon five storylines related to: social context; safety and security; role of nongovernmental organizations; child sponsorships by NGOs; and mothers' resilience through the life stages of their children. These storylines offer direct responses to each of the study's original objectives pertaining to primary concerns and parenting strategies of mothers (Obj. 1); access to health and social services (Obj. 2); implications of threats to their human rights in the everyday (Obj. 3); and factors of social support, poverty, and sociocultural views on the experience of mothering in this context (Obj. 4).

Social Context: Situating Mothers' Experiences

For mothers who have children with albinism in Tanzania, the spectrum of hardship they experience is directly related to the social context in which they live and raise their children. Few women interviewed experienced partners, in-laws, and communities who openly embraced and supported them and their child(ren) with albinism. This storyline situates mothers' experiences

within their social context, and begins to weave in some of the study's theoretical frameworks, including Africana Womanism and human rights, in order to interrogate society's role and better understand the context of a mother's experience (further explored in Chapter Six). Subplots related to social context include (a) social constructions of gender, (b) urban versus rural settings, and (c) the contrasting experiences of women facing deprivation versus those who are, even minimally, resourced.

Constructions of Gender: Africana Womanism

In terms of how gender is constructed within Tanzanian society, interviews with key stakeholders, including religious leaders, NGO/CSO staff, educators, nurses, and government officials, along with conversations with Waithera, supported and gave context to how I interpreted and applied Hudson-Weems' (2019) theory on Africana Womanism. Formally developed in 1989 by Hudson-Weems (2019), Africana Womanism considered gender, race, and class from an African perspective before the concept of intersectionality was introduced— challenging the hegemony of what had become a largely white feminism. Hudson-Weems (2019) argued that Black feminism, African feminism, and Walker's womanism failed to ground their theories in African culture and ways of knowing that considered "the unique experiences, struggles, needs, and desires of Africana women" (p. 24). Africana Womanism "embraces the concept of collective struggle for the entire family in its overall struggle for liberation survival" (p. 29; see Figure 3 in Chapter Three). This particular storyline of social context and subplots begin to demonstrate the enactment of Hudson-Weems' (2019) Africana Womanist values and perspectives, challenging me as a North American white researcher and readers both in and outside of the Tanzanian context to reflect on our positionality as we absorb and interpret to

assess the narratives that flow from this critical ethnography. Women in Tanzania who have children with albinism experience intersecting forms of sexism and discrimination based on the babies that they deliver. Mothering and family are central to the role of a Tanzanian woman. To mother a child is paramount, as articulated by Oyana's statement: "…deep in my heart I said, yes I have a child who looks different but I have left a mark in the world. Even if I died at least I have something." As illustrated in Chapter Four, Imara experienced the abandonment by her husband and the shunning by her in-laws because she delivered children with albinism and, further, all of her children were girls. Imara is not alone. Many participants revealed similar stories.

After delivering their first child with albinism, neither Tishala nor her husband understood the condition to be albinism. In fact, it was not until he was six years old that they received albinism specific education by a mobile clinic. Her husband hoped that their son would "become darker" after some time. However, with the delivery of their second child with albinism, his response shifted:

> But now the father, he was the saddest man. When he went back home and they asked what baby has been born he said, "Ah, the same type of kids that she delivers." When they went back home [after discharge from hospital] it started: the back and forth of family meetings…trying to excommunicate me because I'm not a woman enough [saying] "we can't continue keeping her, she's just defiling our lineage, she's not a woman enough, she can't deliver proper kids." [These family meetings went on for] two to three years…and eventually, they took me back to my parent's home.

The decision that Tishala is not woman enough because she does not produce "normal" (i.e., melanated, able-bodied) children represents what her in-laws view as a failure to her gender and purpose in the family, community, and to broader society. Because of this conceptualization of womanhood and motherhood, Tishala is ostracized and sent back to her parent's home: a decision that would have financial implications for her husband and in-laws related to the dowry paid. More than half (nine of the 17) the mothers without albinism themselves interviewed in the broader study experienced this kind of rejection from their partner and in-laws.

Rural and Urban

Ease of access to resources surfaced as an essential factor in child-rearing. This access was largely dependent upon where the mother and child lived, whether in rural or urban settings. For example, interviews in Dar es Salaam revealed proximity to the country's main cancer prevention and treatment facility: Ocean Road Cancer Institute, Dar es Salaam. Families are able to bring their children with albinism to this facility for regular dermatological assessment, free of charge during weekly clinic hours. While this may require a bus ride that takes a couple of hours, in large part due to Dar es Salaam's notorious traffic, fewer barriers exist when living in or around Dar es Salaam.

Mothers interviewed in the more rural Mwanza region were far more likely to struggle to ensure that their children received regular dermatology assessments. The mothers interviewed in this region were largely from rural villages originally, and had moved closer to resources in years following the delivery of their children with albinism, due also to the higher threat of attacks in more rural settings. Mothers acknowledged mobile vision and dermatology clinics in the Mwanza region as their only access point for these resources, particularly when their child was

not in the sponsorship program for education in boarding schools. Boarding schools where

children sponsored by *NGO-1* attend ensure that children are well supplied with hats, protective

clothing (i.e., long-sleeved uniform shirts with pants), and sunscreen in addition to regular

dermatology and vision clinics by *NGO-2*. This access to resources was confirmed by one of the

head teachers, Maneno, in such a boarding school in the Mwanza region: "their specific needs

like hats, glasses and sunscreen, *NGO-1* and *NGO-2* make their own arrangements to make sure

they come [for screening]. But then [the school] makes sure they use them [protective clothing,

sunscreen, and eyewear]." Mothers on Ukerewe Island noted that "we get lotion from *NGO-2*…

but this happens every six months. So, if you run out of sunscreen before the six months you

have to wait until the next [clinic] in six months."

Knowledge of sunscreen and protective clothing cannot be assumed, as became evident

in an interview with Kamaria, a mother with albinism in a village setting about an hour outside

of Mwanza city (she was interviewed for the broader study and minimally included in this

current study). Kamaria questioned Waithera's claim that they had the same condition of

albinism and both worked in agriculture: As to how her skin is "so soft and smooth" despite

having the same condition that she has, Waithera explored whether she knew what sunscreen

was, her response was, "I have never heard or seen of that kind of lotion." Kamaria went on to

explain that she was unware of a mobile clinic conducting free services in her area recently.

Waithera noted from her explanation that "she does not get clear or directive information

concerning these services…She was not well informed about the clinics, that is why she was not

there." This lack of knowledge highlights the barriers that affect how women are able to access

services and the difficulty that NGOs/CSOs and government services have in ensuring

information dissemination is effective regardless of geographic location.

Engaging local community leadership offers an opportunity to address this missing link.

Street Leaders, local leaders appointed by their neighborhood or block to represent them to

district leadership (interlocutors), are often depended upon to disseminate information to families

from government and health and social services. This process was described in interviews with a

previous NGO staff, Atiena, and a social worker, Glory. However, this communication strategy

is thin. The struggle for access depending on where families live within Tanzania highlights the

counternarratives of women facing deprivation versus those that are resourced (even minimally).

The next section explores such narratives.

Moving from Deprivation to Resourced

Isolation and struggle were common threads in the vast majority of interviews with

mothers. The exception was one participant who herself, along with her husband, were very well

educated (post-secondary and beyond) and gainfully employed. Families suffering serious

deprivation face lack of consistent income, absence of family and community support, and

barriers to or lack of access to health and social services. Families who are even minimally

resourced with one or a combination of the above expressed marked change or differences in

how they experienced daily life. Strikingly, women who were able to identify a singular source

of support, most often in the form of a supportive family member, friend, or organization,

expressed hope, an ease of the burden, and capacity to carry on. As all of the participants were in

some way connected to an NGO, the stories gathered reflect the move from deprivation to

resourced rather than providing counter-stories of women with and without resources. This will be further illustrated in sections below related to how mothers support each other.

       Rehema's story illustrates this move from deprivation to resourced. Rehema has one young son with albinism whose own father and uncle were a part of a plot to profit from a mutilation attack against him. A man dressed as a woman wearing a Muslim hijab and long dress posed as a family member and attempted to kidnap the 18-month-old who was in the care of a "Dada" (in Tanzania a "dada" is a woman who helps around the house and with child care). Thankfully, a neighbor recognized the baby who was crying and stopped the "man" to inquire after the child. Realizing that he did not recognize the "woman," he questioned the attacker and, noticing the bloody hand of the child, literally blew a whistle to call for help from neighbors. The attacker had already chopped off one of the child's fingers. Rehema was experiencing isolation and discrimination prior to this attack, in large part related to unsupportive in-laws who pressured her husband to leave or to recognize and utilize the "money you have in your own house" (referencing the money they could make from the sale of body parts or hair from their child with albinism). Her brother in-law argued, "Why do you sleep hungry and work so hard when you have all the money in the world that you need in your house? If you take that one…and if you just cut a finger you will be very rich." Without support in her home and now a husband directly involved in a muti-attack against their own child, Rehema was desperate in the face of a traumatizing incident. During a visit to the Ocean Road dermatology clinic in Dar es Salaam with her son, she was looking particularly discouraged and Inaya (Mama Anna), the chairperson on the Dar mamas' group, approached her, asking, "Why are you looking so sad?" After some conversation, "[Mama Anna] told me, 'you know, there's an organization called

NGO-1. Go there and I'm sure you're going to get help." *NGO-1* offered to sponsor her son and

he is now attending a boarding school in Dar es Salaam as a five-year-old. Later in the interview,

I probed regarding further resources that she currently has, especially now that her child has been

sponsored to attend boarding school. Her response is telling: "I have no other place except this

group. Anything to do with raising my child with albinism, I have never had that opportunity

until I reached out to *NGO-1*."

Within this same sharing circle (Sharing Circle-3), there was a synergy as they described

the sense of empowerment they felt as participants in the mamas' group. Rehema stated, "The

things we've been doing as a group has earned us respect in society because this group is a

classic example that if you empower women, we are capable. It's not like people are incapable."

Another participant in this sharing circle reflected that "before [this group] I had so much stress,

pressure and fear. But this connection we have and the things we do together keeps me moving."

This idea of how the connection with other women provides encouragement and hope is echoed

by another participant: "[I am] so grateful because of the support and the encouragement I get

from this group…every time I come…I get encouraged and more hopeful that I have a means to

somehow meet the needs of my children and raise them better." These quotes highlight how

mamas' groups have increased capacity through creating a social network and resourcing women

who were otherwise feeling isolated and alone.

Summary of Storyline 1: Context

Social context influences the everyday lives of mothers impacted by albinism. To be a

woman who delivers a child(ren) who is in any way "other" poses several risks to the well-being

of both mother and child. Mothering is central to a woman's identity within the Tanzanian

context, illustrated in part by how women are known as "Mama *name of their child*" (e.g., Mama Anna). Thus, to deliver a child deemed unacceptable in society's view affects her own sense of self and identity as a woman in concert with how her society views her and her child. The degree to which mothers experience the weight of this reality is dependent upon where they live (urban versus rural) and how they experience resources in the form of services, community, or family.

Safety and Security: Carrying the Burden

The data is replete with evidence that the safety and security of children with albinism remained central to mothers' concerns. Maslow's Hierarchy of Needs introduced the concept that only when one's most basic needs are met is one able to thrive and reach self-actualization (Benson & Dundis, 2003). Safety and security are foundational. Tanzania currently has the highest number of recorded mutilation attacks and muti-murders in Africa (UTSS, 2020). In part, this high reported incidence is due to efforts by NGOs/CSOs to monitor and actively investigate and report attacks; other jurisdictions may have similar numbers of attacks but not the same monitoring system.

Mothers in this study knew that if their children were out of their sight, they were at risk of attack. While fewer attacks have occurred in recent years (with the last murder occurring in 2015), women interviewed expressed fear and detailed how the risk was still very much present. They cited recent attempts to kidnap or attack their children along with anxiety about upcoming local elections in 2020 (UTSS, 2020) as reasons for this constant fear. With this storyline, I outline mothers' experiences around threats to security, sources of protection, and access to justice.

Threats to Safety and Security

In parts of Africa, related to the belief that body parts, blood, hair, and nails of persons with albinism can bring good luck when used in witchcraft-related rituals, persons with albinism are hunted and attacked (Brocco, 2016; Cruz-Inigo et al., 2011; Reimer-Kirkham et al., 2019). Children are most vulnerable to such attacks, leaving mothers anxious about navigating methods to best ensure the safety of their children with albinism (UNGA, 2017b, 2019a). The routines of everyday life are cluttered with concerns around how to ensure their child gets to and from school safely, who are safe people to leave their child with, and how can she navigate work with keeping such a close eye on her child. Of course, these concerns are experienced alongside pressing worry over her child's skin safety; exposure to the sun without sunscreen, protective clothing, and a hat results in painful, blistering burns and risk of skin cancer. When much of the work available to women impacted by albinism occurs outdoors (e.g., selling fruit, street vending, agriculture), the requirement to bring their child(ren) with them to work in order to ensure their safety poses a direct and significant risk to their child's health and wellness. Again, this risk is representative of yet another (non)choice that mothers impacted by albinism are confronted with. Confirming the representative experiences that Imara shared, mothers shared several stories of these tensions. The only mother whose experience was different was from a significantly higher socio-economic bracket, and, perhaps most importantly, whose partner was equally committed to loving and raising their children with albinism. Concerns around safety, both physical and health-wise, were not as dire as a result of being a well-resourced family.

Jahaira's experience exemplifies the complex worries around safety and security. At five months pregnant with her child, Jahaira lost her partner. Upon delivery of this child with

albinism, she sought support from her in-laws, as is customary. However, they refused to acknowledge her son as family, stating " 'you've delivered a *mbuliwmelu* [Sukuma for 'white goat'].' I responded, 'no, I have delivered a child.' But my in-laws, said, 'this one, this here, we do not have these people.'" With her in-laws choosing to refuse kinship, Jahaira was left without support. When her son was seven months old, a man came to visit her and expressed interest in marrying her. They began communicating by a phone that he purchased for her. Eventually this man sent her a message expressing his real intentions: "I actually don't want to marry you, I want a part of your child…for further instructions call this number." Afraid and with very few resources, Jahaira went directly to the Street Leader to report the threat and seek safety for herself and her son.

During this time, between 2013 and 2014, there was an increase in attacks against persons with albinism in the Lake Zone region. With communities and families trying to avoid being blamed or liable for an attack, mothers and their children with albinism were left to find solutions themselves. For Jahaira, the Street Leader was helpful. He provided immediate support in the way of allowing her and her son to sleep at his house in the immediate aftermath and escorted her to the police station to report the threat. With the case documented by the police, her own family and community were urging her to go with her son back to her in-laws: "…these people already paid dowry for you, so you are supposed to go raise that child [with them]." Essentially, this solution would relieve her family and surrounding community of ever being blamed should an attack occur. They gave her an ultimatum: "…you go to your in-laws or we take your son to [a government holding centre for children with albinism]." Her in-laws again refused them.

It was in the middle of these negotiations that a man with albinism who had heard Jahaira's story offered to help her and her son. Through a series of events initiated by this man's support, Jahaira was able to live on her own again, selling bananas while keeping her son with her at all times. Not long after this threat, she received a phone call from *NGO-1* stating that they had heard about her story and wanted to offer sponsorship to her son who was now just under three years old.

> It was very hard for me. It was painful because I couldn't imagine how it would be for him to be separated from me. I took time to even accept the *NGO-1* offer but my neighbors where I was living kept telling me, "this child is better off taken care of than staying here and being unsafe." After a lot of convincing by the neighbors, I accepted the offer…After one month after [he] went to the school, I went to see him and he had forgotten me.

At this point in the interview, Jahaira was detailing these events of being separated from her son through tears. Waithera and I listened, trying to hold back our own. The women in this sharing circle were gathered close, affirming Jahaira's experience with their own knowing nods and utterances of shared experience—confirmed as each subsequently shared their own harrowing stories. Jahaira was encouraged to visit more frequently than the one time per month that she could afford and manage:

> Sometimes on [visitation days] I do not have the means, but I go out of my way to make sure I go…sometimes he asks me 'Why don't you come with my father to see me, why is it only you who comes to see me?' To console him, I have to figure out how to go anytime *NGO-1* informs me that it [is a visiting day].

Separation from her son represents one of many (non)choices that mothers face: a choice between parenting in the everyday or ensured physical safety.

Sources of Protection

As Jahaira's story exemplifies, options for protection are both formal and informal. From interviews with key stakeholders, local leaders (i.e., Street Leaders and District Leaders) have been tasked with supporting families impacted by albinism within their communities: knowing which families are impacted, where they live, and attempting to help keep them safe. Much different than in previous years, when neighbors were helpless bystanders or even involved in scheming attacks, neighbors have become a vital link in ensuring the safety of persons with albinism: a final check on spotting potential attackers and, literally, sounding the whistle that acts as the call for immediate help. In the case of Jahaira and Rehema, their neighbors and Street Leaders were instrumental in preventing further harm.

Social workers, as regional government employees, seek out connection with Street Leaders. Because Street Leaders know their own communities well, including which families are impacted by albinism, they are key to engaging when safety concerns or health related resources arise. The social worker interviewed explained it this way:

> …[F]or example, when the government wants to reach out to them [persons with
>
> albinism or parents of children with albinism], my work is basically to link back to the
>
> Street Leaders because…the Street Leader already knows what homes have a mother who
>
> has children with albinism or a woman with albinism…when the government needs to do
>
> something, even when they need to distribute things like sunscreen or have any kind of

meeting, they go back to their Street Leaders…they know even if one moved, they will

know who, if there's a new one… this is really localized.

As the social worker for persons and families affected by disabilities, she expressed a particular

need to follow up with families impacted by albinism due to the safety risks. She explained how

she prioritizes meeting mothers in perinatal clinics and at the hospitals who are impacted by

albinism, ensuring they have her contact information along with education regarding albinism as

a condition. She provided a few examples of mothers and grandmothers contacting her with

concerns around the safety of their children (or grandchildren). In these scenarios, she described

how her involvement initiated investigations, securing the support of Street Leaders, and linking

these families to NGOs and further resources available to them. Of note, she discussed the use of

government holding centres for temporary shelter and safety for children that are deemed at high

risk of imminent danger. Glory stressed that these separations from their family were temporary

and for as short an amount of time as possible. She detailed mothers' groups for parents of

children with disabilities who can draft a business plan and apply for government loans with zero

interest. She also talked about meetings with nurses and physicians in which, as social workers,

they try to provide sensitization training so that healthcare providers are better equipped to

respond thoughtfully to women impacted as well as ensure they are discharged with key

information in hand about the condition.

Further sources of protection include NGOs such as *NGO-1*, grassroots organizations like

the Tanzanian Albinism Society (TAS), and neighbors who become watchmen and

whistleblowers when they note suspicious activity. These three support systems will be further

discussed more specifically in the upcoming section on the role of NGOs.

Access to Justice

Both Jahaira and Rehema's stories highlight police involvement in response to threats to security, at minimum to record a statement. Few stories shared during fieldwork suggested that justice was pursued and actually carried out. Like Imara, most of the mothers had stories of close calls where their child(ren) was nearly kidnapped or harmed. Rehema's experience, however, illustrates how haphazard justice can be in these scenarios. As Rehema relayed, the attack against her son was documented at the police station immediately following the attack. In the case of the man that committed the physical crimes of mutilation and attempted kidnapping, the police did in fact carry out charges against him. When TAS did a follow up some time later, they found that he had been sentenced to life imprisonment in a national penitentiary. It appeared that justice had been served for this angle of the crime. However, once Rehema's sister-in-law revealed that her own husband (who had already passed away at that point) and Rehema's husband had actually schemed together, brothers instigating the attack, Rehema was left with no choice but to report him to the police. As Waithera translated:

> She says, "you know when my in-law came to tell me my husband was involved, I
>
> decided not to blind my eyes, because, you see, I am with this man in the same house as
>
> this child." So, she went to the police station…to report. The police gave her a letter to
>
> take to the local leader so that he gets an official summoning to go to the police station.
>
> It's a daring move.

With police and TAS representatives supportive of Rehema charging her husband, he would have been sent to prison. However, the child, age 3 at the time, ended up playing a pivotal role in this drama. The child kept asking why his father was crying, why he was so upset. When told

that he had done wrong, the child begged for his father to be forgiven. While Waithera argued

that this is not typical that a child would have such sway, Rehema said that "because it was

Siwatu's voice and decision to forgive the father, we all had to…But nothing changed, I

continued living in fear." Of note, even police were surprised by this decision, asking "are you

sure you want to forgive your husband." When Rehema reiterated the child's decision, police

decided to, at the very least, "make sure there was a commitment from him to be the first

protector of this child…from today, officially, if anything ever happens to this child he would be

the first responsible person."

Within another year, this man was denying paternity, telling Rehema and Siwatu that he

was not the father. With this denial came removing any support for Siwatu (e.g., refusing to pay

school fees, refusing to buy him clothing). Eventually, Rehema and this man formally separated.

This man has never been held legally accountable for his actions. In debriefing with Waithera,

this idea of a child having such strong influence does not appear to be common. However,

resolving crimes such as this at the family or community level has been commonplace (i.e.,

family reconciliation) and was discussed by a frustrated Nia, a human rights advocate for a local

NGO. This is the very situation that *NGO-1's* advocacy work has sought to influence: Those

threatening or committing violence must be held accountable and brought to justice in order to

send a strong message to perpetrators (UTSS, n.d.a). I was told that in this scenario, that police

would allow a man who has confessed to the crime leave with no charges, regardless of whether

the spouse and child are the ones placing such a charge, suggests that law enforcement rather

easily relinquishes their legal obligations. Arguably, being in the position of having to charge a

family member with any kind of crime is an impossible decision—particularly in a patriarchal

society, in which the man of the house is the breadwinner and in the position of authority.

From a Canadian perspective, in situations involving intimate partner violence and any

violence against a minor, charges are laid by the justice system, not necessarily by the family or

survivor. This removes the responsibility of family members placed in such an impossible

situation, and considers risks of retribution, thus protecting victims of violence (Canadian

Victims Bill of Rights, 2015). Judging this situation solely from a Eurocentric, Northern

perspective risks oversimplifying what must be considered about being a single mother in

Tanzanian society. However, it further highlights the contrasts in terms of what women in

Tanzania are able to access in comparison to other parts of the world. Particularly, when a

woman does not have a skillset to bring to the workforce and when she cannot ensure the safety

of her child inside or outside home, we are, once again, faced with the various (non)choices that

mothers face daily coupled with an unregulated justice system (UNGA, 2019b). For example,

Nia reflected on a recent situation in her work as a human rights advocate, where a mother was

faced with an impossible situation: maintaining a cohesive family in which shelter and food was

provided by her husband or reporting him for selling the hair of their son with albinism.

> It's a secret that has never been reported to the police. Legally you cannot forcefully
>
> shave somebody's hair to sell it…It was so close to the skin that it was creating a visible
>
> scar. And that was worthy to be reported. It is abuse…So you get mothers who know
>
> what is going on but cannot say anything because of the culture of secrecy. They cannot
>
> speak against their husbands…

This situation demonstrates how provision and protection is not always straightforward. NGOs and government services must navigate these barriers to justice, getting creative on how to support families from identifying and reporting human rights violations through to the justice process and thereafter to ensure families are well resourced and protected.

Summary of Storyline 2: Safety and Security

Mothers with children who have albinism bear much of the burden concerning the safety and security of these children. As the examples of Imara, Jahaira, and Rehema demonstrate, such concerns are warranted. Tanzania has legislated particular policies in regards to persons with albinism and continues to struggle to ensure that perpetrators are held to account and consequences are made public (UNGA, 2017b). NGOs such as *NGO-1* are instrumental in promoting the safety and security of persons with albinism and have been directly involved in ensuring justice is sought and perpetrators are indeed held accountable (UTSS, 2020). Social workers and Street Leaders play key roles in the protection of these families as well as ensuring resources available actually reach them.

Role of Non-Governmental Organizations: Resourcing a Gap

It is within these complexities where the lack of resources is so clearly exposed that the role of NGOs/CSOs becomes clear. Women voiced that before the assistance from NGOs such as *NGO-1* and *NGO-2*, they had very few to no formal resources available to them. For example, women in Dar es Salaam cited skin care clinics at a hospital in Dar es Salaam that they could access, but named no other resource. For women in rural settings, resources outside of NGO support were nil, save for an occasional physician visit that may or may not have provided albinism-specific care. NGOs such as *NGO-1* and *NGO-2* have filled the gaps for several years,

supporting the government as it attempts to address the atrocious human rights violations against

persons with albinism. The role of NGOs in this context, both international and local, have

broadened over the years moving towards influencing local policy and addressing human rights

concerns from a global platform (UNGA, 2016a; UTSS, 2019). This move is certainly evident in

the case of NGOs addressing albinism in Tanzania. Brocco (2015) highlights this NGO attention

to advocacy in his work, particularly in a published photo essay exploring the interactions and

"global flows" of information between persons with albinism and the work of NGOs. From

interviews with mothers in Mwanza and Dar es Salaam, the only resource that they were

regularly accessing not associated with an NGO was Ocean Road Cancer Clinic for dermatology

services. Otherwise, any resource accessed was a direct result of NGOs themselves or referrals

made by NGOs. The following details how mothers access NGOs such as these, the fact that

many health and social services exist as a result of NGOs, and illustrates, per participants, the

significant impact that mamas' groups have.

NGOs as Resource

Mothers interviewed were clear that without the support of *NGO-1* and *NGO-2* for key

resources such as education sponsorship, consistent skin and eye care, and psychosocial support

via NGO staff and mamas' groups, they would, once again, be on their own. Prior to connecting

with either organization, mothers detail not understanding what albinism was or how to take

particular care of their child(ren)'s resulting needs (health-wise). As Tishala mentioned, she did

not receive education until her son was six years old when "some people called us to a

meeting…and we were educated on albinism in 2007" (I am unsure who organized this

meeting—NGO or local healthcare staff). Rehema, responding to the question regarding what

kind of resources or supports had she received, confirmed, "No, besides this group and the way I get school fees support from *NGO-1*…No [I don't have any] personal support." In a separate, rural location on Ukerewe Island, Naima, shared that "I have not received any community support but from *NGO-2*." Location of home was significant in terms of access to resources with urban mothers faring slightly better, accessing hospitals versus clinics with lay medical professionals sometimes hours away from their home villages.

Further, both NGOs have assumed the particular role of providing education to healthcare professionals. *NGO-2* has developed a model in which local dermatologists are trained on albinism-specific care and evidence-based practice. *NGO-1* takes every opportunity to provide HCPs with their Understanding Albinism courses either formally or informally when they encounter an HCP. This kind of education necessary is best illustrated by the comments of Nia, an NGO staff member, who herself has albinism, in the following statement:

> [When we encounter health practitioners] we tell them about albinism because we have health practitioners who know nothing about albinism. …We've met doctors and nurses who bring questions like, "I thought you guys don't die, you disappear." That is a medical practitioner. If you meet a midwife that believes that people with albinism disappear, you don't expect her to help you out when you have a baby with albinism… So, when we meet those scenarios we address them by educating them…and trying to teach them that when you meet this sort of case in your practice, you're supposed to address this in one, two, three ways. So that way we assure that that particular doctor or nurse or midwife will be able to assist. …There's a huge gap [in knowledge and services available] regardless [of geographic location in Tanzania].

Nia went on to describe the various levels of specialty physicians throughout Tanzania, emphasizing that dermatologists are few and typically serving large cities. Those living in rural areas are dependent on paramedical professionals, general practitioners, and mobile clinics provided by NGOs.

A third organization, TAS (the Tanzanian Albinism Society), is a grassroots CSO established in 1978, run for and by persons with albinism (Brocco, 2015). With minimal funding from the government of Tanzania as well as international donors, TAS uses its resources to advocate for the rights of persons with albinism, raise awareness about the genetic condition, assist in pursuing and ensuring justice following threats or violent attacks, and help to coordinate health care for persons with albinism by connecting those impacted with available services. Participants in this study cited TAS particularly in reference to the organization following up cases following an attack—making case follow-ups after perpetrators are charged and sentenced (e.g., in the case of Rehema, TAS followed up months later to ensure the attacker was actually in prison following his sentencing).

Accessing NGOs

NGO-1 has, over its 10 years in Tanzania, become a well-known, well-respected organization in the country. Outreach has remained a key component of *NGO-1*'s work throughout Tanzania, including responding following an attack, and visiting schools throughout the country to identify where children with albinism are attending school. The first point of contact to *NGO-1* by families has generally been via their education program in which children with albinism are sponsored to attend boarding schools throughout the country. However, media campaigns using several mediums including social media, TV, radio, posters, and ads in

newspapers have brought attention to the issues surrounding albinism as well as awareness to the services *NGO-1* is providing. While about half (*n* = 13) of the mothers within the broader study's sample of mothers with children with albinism (*n* = 23) learned about *NGO-1* after their children with albinism were offered sponsorship, Rehema's story stands out. As mentioned, it was another mother from the *Wamama Wanaojali* group, Inaya, who referred her to *NGO-1* after seeing her "so sad" at Ocean Road, the cancer clinic in Dar es Salaam where many persons with albinism receive skin care from dermatologists. Rehema's son is now sponsored and she is part of the *Wamama Wanaojali* group herself. This was one example from the interviews where mothers demonstrated how they advocate for their families and for each other. Mothers impacted by albinism share a unique experience, and with limited resources and supports available it was incredible to witness their generosity and care for one another.

Families access the services of *NGO-2*, with more of a healthcare focus, via their mobile vision and dermatology clinics, detailed in the next section. On a small island in Lake Victoria, a few hours' ferry ride from Mwanza city, *NGO-2* has a beautiful, environmentally sustainable community centre. Built with persons and families impacted by albinism in mind, the community centre is for the whole island. A place to gather, to read in the library, to learn about albinism, a place for the music collective to practice, the sewing group to create, and garden space to grow vegetables. Walking around the centre, it is an aesthetically inspiring and welcoming place— unlike much of what I experienced elsewhere. Even in this welcoming space, however, considerations for protection from the sun had not been fully accounted for, given open air and large window designs that those with albinism noted caused exposure to sunlight (affecting skin and eyes). This highlighted for me how difficult it is in a tropical climate especially to fully

protect persons with albinism. Regardless, it is space open to the whole of the community aimed at shifting the narrative of albinism on the small island, which it is indeed accomplishing.

Health and Social Services via NGOs

As mentioned above, *NGO-2*'s key focus is healthcare-related. As such, their mobile clinics serve or have served the majority of women interviewed in the broader study. Most of the children receive skin and vision care at clinics in their boarding schools or mobile clinics near their homes. Nia explained how *NGO-2* reaches out to them at *NGO-1* to relay dates and locations of clinics to ensure that, between the organizations, the largest number of persons with albinism can be reached. In this way, the two organizations coordinate their contacts to ensure as many people are able to access the resources as possible. This partnership is key in continuing to move the needle on albinism in Tanzania. Organizations that avoid siloing and instead bring their expertise to complement other resources ensure the largest impact. *NGO-1* and *NGO-2* also coordinate to bring skin and eye clinics to boarding schools where there are sponsored children with albinism. Sunscreen, wide-brimmed hats, and protective clothing are also provided and the importance of their consistent use reinforced at these clinics. Nia discussed what families commonly approach *NGO-1* for in contrast to what the organization offers:

> Most of them ask for financial assistance. But what we do here is organize, for instance, free skin care clinics and we invite them over and they come and they get checked by doctors. That's helpful. Or we build liaisons with dermatologists that are interested. There's also another NGO, *NGO-2*, and it is centred on health care. We have a close relation[ship] with them. So, when they do the skin care clinics they even contact us to find some people for them to go take care of. And, there's some dermatologists who are

just simply interested in helping people with albinism. We have one lady, she works for a

certain clinic [in Dar es Salaam]. …she is willing to assist any patient with albinism

and…it's free. She doesn't charge.

Perhaps in part due to the lack of education regarding albinism, mothers with children

with albinism, as previously demonstrated, often do not know where to begin in terms of caring

for the health needs of their children. Without nurses, physicians, or midwives who reinforce

after delivery what next steps are, mothers are left in survival mode: faced with incriminating

questions and abandonment by partners, family, and community, only the absolute essentials are

fought for initially. That is, food and shelter. Interestingly, although the social worker

interviewed, Glory, was adamant about services available to women and their families impacted

by albinism, not one mother (of the 26 interviewed) had ever received a referral to or received

services from a social worker. These social services were provided, formally and informally,

instead by *NGO-1* and *NGO-2* in the form of sponsorships to boarding schools, skin and vision

clinics, and *Wamama Wanaojali* mamas' groups. NGOs play a key role in bridging these gaps.

Key to *NGO-1*'s outreach program, is establishing where persons with albinism are living and

establishing connections to health and social services resources.

Mamas' Groups

Central to the study findings is the contribution of mamas' groups, both as a site of data

collection, what was learnt about the experience of mothers impacted by albinism in this context,

and the profound impact these groups were reported as having on the wellbeing of these mothers.

As one mother in Sharing Circle-4 stated, "If you empower women then you've empowered the

household." Empowerment, as one of the key experiences of mothers engaged in the *Wamama*

Wanaojali groups, is essential in protecting mothers and their children impacted by albinism.

These groups are supported by a few different NGOs including *NGO-1* and *NGO-2* and exist to

support mothers impacted by albinism psychosocially, emotionally, and economically. Started

about five years ago, these groups were initiated by Waithera, who was working for *NGO-1* at

the time in a consultancy role, and another *NGO-1* staff member. Waithera remembers meeting

these mothers individually and realized that each of them were experiencing the isolation,

loneliness, and depravity that so often accompanies the albinism story in Tanzania. Waithera

advocated for the mothers to begin meeting together and engaged another staff member of *NGO-*

1 to assist in facilitating. Eventually, Sarah, a Canadian missionary, discovered the group

through various contacts and took on a facilitating role, engaging the mamas in Mwanza while

providing some distance facilitation to the group that had started in Dar es Salaam. Sarah's

vision was to not only help create a space for women with shared experience to relate, build

relationship, and support one another, but also to come alongside them and develop skills that

would produce marketable items. Sarah recognized the poverty that these mothers faced and

committed to partnering alongside them to develop a small business that could turn that tide,

while engaging them in financial management skills, inventory, marketing, and customer service.

  In interviews, mothers were *very* vocal about their experience as a member of *Wamama*

Wanaojali and were clear about these groups as a singular source of holistic support, of which

they are wholly invested. In Sharing Circle-3, from the mamas' group in Mwanza, participants

shared the following reflections about connection with the group.

  Sharing Circle-3 Participant: I am more grateful because of the support and the

  encouragement I get from this group because of all these things I've been through…every

time I come to the group, I get encouraged and more hopeful that I have the means to

somehow meet the needs of my children and raise them better.

Here, this participant demonstrates how, through her involvement in the mamas' group, she is

supported and encouraged in a way that increases and maintains her capacity to raise her

children. The support is both social and financial.

Sharing Circle-3 Participant: …before now, I had so much stress, pressure and everything

and fear. But this connection we have and the things we do together keep me moving.

For this participant, the mamas' group has brought hope by way of social connection as well as

relieving some of the burden that she carries alone. There is opportunity to earn an income

alongside women with shared experience who can offer support and encouragement.

Sharing Circle-3 Participant: The things we've been doing as a group has also earned us

respect out there in our society because this group is a classic example that if you

empower us, we are capable. It's not like we are incapable. And the things we make here

are made by both persons with albinism and parents who have children with albinism and

indicate [to society] that, "yes, they have albinism but, yes, they are making fabulous

stuff."

This last quote is exceptional. This mother is articulating that the work they have been doing as a

collective has "earned us respect" in their communities. Previously isolated and alone due to

stigma and discrimination, these women experience the exhilaration of selling their own

handmade products to impressed, paying customers curious about their work. These women have

the opportunity to look society in the eye and declare their place. The self-esteem, confidence,

and communication skills that this kind of collective has fostered are remarkable. Learning the

soft skills of business can change the trajectory of these starter businesses. These women, who

have experienced neglect and abandonment often by their closest family in addition to their

communities, are experiencing, perhaps for the first time, radical acceptance, respect, and shared

responsibility. What could be more empowering for these mothers? Through fieldwork with

these women, it was abundantly clear that they are an untapped resource in terms of advocacy,

communication education, and social outreach. As mothers, they know what their families need.

They know what policy makers, government officials, and NGOs need to know in order to

improve the lives of families impacted by albinism in Tanzania. These mamas' groups could be

an access point for these stakeholders to engage women, seeking their expertise in their own

lives.

Furthering the narrative that these mamas' groups are often the sole resource for these

women, Rehema from the Dar es Salaam group responded to the question "Now that your child

has been sponsored to attend school, do you have any other form of support?" by stating the

following: "I have no other place except the group. Anything to do with raising my child with

albinism I have never had that opportunity until I reached out to *NGO-1*." Waithera gathered

from this statement how fractured the minimal resources appear to be: "See it's interesting. Like

even when they go to this Ocean Road [Cancer Clinic], you go for skin clinic but then nobody

cares to make sure you understand the basics." These basics are often filled in by a woman's

social network. In the case of these mamas' groups, the shared experience, pooled resources, and

engagement of *NGO-1* and *NGO-2* allows for engagement in a knowledge exchange that

otherwise exists in isolation where myths and cultural beliefs about albinism continue to fester.

Unconnected from *NGO-1* and *Wamama Wanaojali*, Sharing Circle-8 on a small island near Mwanza city represented women supported only by *NGO-2*. As a mamas' group, these women also acknowledged the impact of their collective engagement with each other. Goma acknowledged, for instance, the "power in groups": "For example, we all have our small businesses and these businesses of course are not sufficient. But I know there's power in groups... [we will be more successful] if we can do something collectively for a common cause to meet the needs of our children." This group was very entrepreneurial and had ideas about starting a mill business together—aware that they would be able to produce more grain as a group than individually. Business acumen exists, but they request capital. Upon my second field visit, *Wamama Wanaojali* in Mwanza had started to connect with this group on the island, seeking to learn from each other and potentially build a larger network. This is directly in line with Hudson-Weems' (2019) key characteristic of the Africana woman being rooted in sisterhood and highlights how participants themselves can steer organizations away from becoming too siloed.

Summary of Storyline 3: Role of Non-Governmental Organizations

Mothers were clear that *NGO-1* and *NGO-2* are where they receive the majority of resources they access or have accessed in the past. Without the work of NGOs and CSOs, the situation would be far more dire. These organizations provide a spectrum of resources otherwise unavailable, from education to health care, from awareness campaigns to advocacy and insisting perpetrators are held accountable. The work of NGOs and CSOs influence policy and continued international engagement to ensure the enjoyment of human rights by persons with albinism. Particular to mothers impacted, however, the *Wamama Wanaojali* group is specific in addressing

their needs as women, as mothers, and as breadwinners for their families. This particular

approach appears to be unique within these organizations and, based on interviews with the

mothers, could be suggested as a "best practice" within other regions and other countries. These

NGOs should, however, continue to work towards engaging mothers as a resource, asking

questions such as: What are their priorities? What do they identify as needs or gaps in resources?

These women are the experts on their lives and the lives of their children. As demonstrated in

this study, reaching out to them as the experts is both empowering and capacity building.

Sponsorship and Mothering: Responding to Separation

The empowerment of mothers has been influenced by how NGOs engage in the care of

children and their families with albinism. While I did not set out to study child sponsorship in

detail, it was quickly apparent that understanding the mothering experience was not possible

without an appreciation of what sponsorship meant to mothering. Education of children with

albinism has historically been difficult due to lack of understanding on the part of educators and

parents as to the specific needs of children with albinism. For example, as confirmed by Maneno,

a head teacher interviewed, teachers must understand the low vision component of albinism and

ensure children have a seat at the middle front of the classroom, are given large-print textbooks

and handouts or exams, and are given assistance to capture notes from the board or projector.

Without these needs met, children with albinism are not able to engage in their learning and poor

performance is misinterpreted as being a poor student. On top of this challenge is the concern

regarding safety. Walking to and from government day schools is risky to their health (sun

exposure during peak times of the day) and their physical safety. With violent attacks and

various threats to their security, mothers are in a difficult position when it comes to determining

how their children will receive an education safely. The following storyline details how

sponsorship became and continues to be a response to these concerns with the overarching aim

of understanding how mothers experience this resource which simultaneously causes the tension

of separation from their children.

Government Holding Centres and the Beginning of Child Separation

In response to the rise in attacks against persons with albinism in Tanzania, the

government coordinated an effort to bring all children with albinism to holding centres or "safe

houses" towards the end of the 2000s (2007/2008) (African Committee of Experts on the Rights

and Welfare of the Child [ACERWC], 2016; Pedneault & Labaki, 2019). There are currently 32

holding centres in Tanzania (ACERWC, 2016). During interviews and in informal conversations

with key stakeholders and mothers alike, I became aware of the chaotic nature of this scramble to

bring children to these holding centres. Government schools for the blind and hearing impaired

were typical sites for these holding centres. Initially viewed as a temporary solution until attacks

could be prevented, these holding centres remain in existence. With the aim of providing

immediate protection to children that were being attacked and/or kidnapped at an alarming rate

and in response to international criticisms of the situation (Pedneault & Labaki, 2019), the

government engaged Community Development Officers, instead of social workers with

particular training on family welfare, to assist in gathering all children to central locations to then

be brought to these holding centres. This sequence of events was confirmed by a key informant,

Atiena, who began work engaging with these families during the crisis point in 2008 with an

NGO. Street Leaders were instrumental in this effort, alerting their residents to bring their

children with albinism to a central location on a particular day. From the interviews and informal

discussions, buses arrived to transport all of these children to holding centres. Affirmed in

Atiena's interview, in many situations, parents were largely left in the dark regarding this plan.

Research published by Human Rights Watch (Pedneault & Labaki, 2019) confirms this finding

that children were "removed from their families, sometimes with no consultation or consent, and

placed in shelters where they were effectively isolated from society" (p. 10). Documentation was

severely lacking in this crisis response. Key demographics (e.g., children's names, parent's

names and contact information, home village) were not routinely recorded. In the months and

years that have now followed, there are several children who have completely lost contact with

their parents. Families were separated, siblings were separated—sometimes going to different

holding centres—with no clear plan to ensure reunion would be the ending. There is now a

generation of children with albinism deeply affected by separation from their families and

communities. Certainly some children have been abandoned by parents too afraid to parent their

children with albinism; however, to end the story there would oversimplify the situation.

Mothers interviewed in this study expressed deep love for their children, often at the cost of any

supportive relationship in their lives. Mothers wanted their children to be safe and to receive

access to the education that could break the cycle of poverty in which so many of these families

are entrenched. Many of these children were not abandoned by unloving parents; rather, they

were either removed at the behest of the government or following the impossible decision by

mothers desperate to keep their child(ren) safe. Unfortunately, safety was something that most

mothers could not guarantee in their homes. To this day, there has never been an attack in

government holding centres, pointing to the basic safety that was indeed ensured. Worth noting

is the pressure that the Tanzanian government placed on local leadership to ensure children with

albinism were brought to the holding centres. Described to me by Atiena and confirmed by

Pednault and Labaki's (2019) research with Human Rights Watch, local leadership (i.e., District

Commissioners and Street Leaders) were navigating a government order that, should a child with

albinism be harmed in their communities, everyone in the community would become suspects

accused of violence. Fear of false accusations contributed to this uncoordinated, hurried effort.

In 2013, due to the troubling conditions that *NGO-1* had witnessed in their visits to

various government holding centres, *NGO-1* approached the African Committee of Experts on

the Rights and Welfare of the Child (ACERWC) to investigate conditions and children's well-

being inside the temporary holding centres (or shelters) (ACERWC, 2016). This committee's

mandate is based on articles 32-46 of the African Charter on the Rights and Welfare of the Child

and was adopted by the Heads of State and Government of the Organization of African Unity

(OAU) in 1990 (African Charter on the Rights and Welfare of the Child, 1990). The ACERWC

accepted *NGO-1*'s request and carried out an investigation in 2015. In their published report, the

committee details their investigation of the largest holding centre in Tanzania, which is the

Buhangija Centre in Shinyanga (ACERWC, 2016). This committee found that children were

undernourished, ill housed in overcrowded dormitories or tents, lacked sufficient numbers of

books and teachers to ensure their education, and also found alarmingly high rates of skin cancer

among children due to inconsistent attention to preventative measures (i.e., sunscreen

application, protective clothing, wide-brimmed hats, avoiding sun exposure) (ACERWC, 2016).

This report was critical of the centre, and called upon the government of Tanzania to respond

swiftly and decisively to improve the conditions for these children and attempt to "chart a way

forward in collaboration with all stakeholders" (ACERWC, 2016, p. 3).

Glory, a social worker, talked about holding centres as still being an important piece in the safety and security puzzle today, but certainly not as a long-term solution. Perhaps her utilization of these centres as temporary shelters suggests part of a shift in how these centres are viewed four years following the committees' report. For Glory, when she needs to remove a child from an unsafe home or village quickly, she acknowledges the importance of accessing these holding centres (used in this way as a "safe house"). However, Glory was clear that she viewed these holding centres as very temporary and only when the safety risk is very high. This separation from parents and family appears to be viewed as a "last resort" when safety and security cannot otherwise be assured. The following excerpt from Glory's interview details this perspective:

> We also work with other stakeholders and specifically the holding centres that exist… In real situations the parents come and report that they are scared, "I'm worried for my child's safety." At that point we recommend the child is taken to the centre…[during] election periods most parents are worried. But then after the election period, the family is ready to bring back the child home when the situation is calm. …We look at it as a temporary solution.

In an example case provided by Glory, she makes the clear point that an investigation is part of her process as a social worker: "[I] was really interested in this case and wanted to really establish if there was a real threat to the child back at home." She follows up with the child's mother, the Street Leader, and the child's grandmother—seeking to establish the threat and decide if it warrants removing the child from their home and bringing them to a holding centre until she, in concert with the community and family, can ensure the child's safety. Unfortunately,

this kind of detail was not followed when children were initially brought to the holding centres,

nor was there a plan to ensure families would be reunited once safety could better be ensured.

NGOs' Response to Crisis

In response to the conditions found in these holding centres, *NGO-1* began sponsoring

children to leave these centres and instead attend private boarding schools. These schools were

vetted by *NGO-1* and represented a pivotal move away from educating children with albinism in

schools for children who are blind and/or deaf, instead providing integrative education ensuring

proper vision aids and teacher awareness/support (UTSS, n.d.b). In addition to these boarding

schools providing excellent education and opportunities for children with albinism to learn

alongside their peers without albinism, the integrated model countered the various myths and

beliefs surrounding albinism (UTSS, n.d.b). Children without albinism would be exposed to and

engage with their peers with albinism starting at an early age, thus debunking myths reinforced,

in large part, due to minimal or no interaction (UTSS, n.d.b). To date, *NGO-1* has sponsored 400

children with albinism (UTSS, 2019). These sponsorships extend from preschool age through to

advanced post-secondary education. Some grantees, as sponsored students are known, have

continued on to graduate level education. In a society that has held rigidly to the belief that

persons with albinism cannot achieve anything, such success in the albinism community has

begun to dissolve these false notions. Staff with albinism at *NGO-1* proudly bear the weight of

their success and pour their passion into seeing all fellow persons with albinism equally

successful into their daily work. My experience working alongside staff at *NGO-1* was saturated

in this passion, commitment, and steadfast belief that their work and very success was

contributing to turning the tide in Tanzania and across borders. This sponsorship program has

saved lives and has been instrumental in educating the next generation of persons with albinism to lead their country into a new, fully integrated and accepting narrative. *NGO-1* is central to this shift. The section below describes in more detail how mothers interviewed view sponsorship.

Apart from sponsoring children in their education programs, *NGO-1* is committed to various other programs and initiatives that further their education, support, advocacy, and awareness missions. Understanding Albinism is *NGO-1*'s albinism education that is delivered to various stakeholders (e.g., teachers, government officials, healthcare professionals, community leaders) that aims to provide factual information regarding albinism and what persons with albinism face—dispelling myths and common cultural beliefs about the condition. *NGO-1* and their legal team has worked to seek and attain justice for survivors of attacks, lobbying for perpetrators to be held accountable (UTSS, 2019). They have lobbied international bodies such as the United Nations to bring the concerns of persons with albinism to the global stage (UTSS, 2019).

NGO-2 is another major NGO in Tanzania working to end discrimination and violence against persons with albinism. A large component of their mission is health-related (i.e., vision and skin screening clinics), but they have robust education, advocacy, and community support programs that are working alongside persons with albinism to address their identified needs and amplify their voices on a global stage. *NGO-2* has been instrumental in bringing much-needed health care and health education to hard-to-reach rural areas of Tanzania. Again, filling a gap that the government has not yet been able to fill, that is, access to adequate health care, which continues to represent a concern beyond those related to albinism.

In short, NGOs have been instrumental in stepping into the gaps left by ongoing human rights violations against persons with albinism. In a nation working towards becoming a semi-industrialized middle-income country by 2025 (Ministry of Science, Education, and Technology Tanzania, 2018), NGOs have been able to initiate and focus government efforts in this particular area while also filling in gaps that the government is not yet able to fill. While taking the pressure off of national and local government, families, as the key recipients of NGO efforts, must be considered in evaluating such responses. In the next section I explore how mothers experience the *NGO-1* sponsorship program, specifically.

Mothers' View of Sponsorship

This study has provided a small window into how sponsorship is experienced from the mothers' perspective. Mothers interviewed expressed, in large part, relief and gratitude for sponsorship. Those mothers who were connected to *Wamama Wanaojali* but whose children were not currently sponsored, implored researchers to assist their children to become sponsored. There were, at the same time, tensions expressed by mothers of sponsored children. While the overwhelming narrative from women interviewed is one of gratitude and relief, there was a related tension expressed about the separation from their children. These tensions are between (a) the relief in knowing their child(ren) are safe, receiving a good education, and a corresponding relief of the financial burden; and (b) the loss of parenting in the everyday, separation from their children, and barriers to accessing their children and knowledge about their progress in school. Eclipsed by these tensions, however, is the fear for their children's safety and the everyday anxiety about their security: again, representative of the (non)choices mothers face.

Due to the lack of detailed information for each child brought to holding centres, some of the mothers interviewed noted that sponsorships were initiated with little input from them. Several factors could have contributed to this, including the original crisis response that understandably led to incomplete documentation. *NGO-1* stepped into a critical gap to address the situation faced by these families and ensure the safety of children with albinism, and in so doing were inadvertently left with the challenge of incomplete documentation. This kind of uncoordinated crisis response is well documented in global health disaster management literature, with encouragement for multi-sectoral policy coordination and implementation to prevent response-related trauma (Aitsi-Selmi, Egawa, Sasaki, Wannous, & Murray, 2015). As noted above, *NGO-1* has continued to initiate and participate in, as evidenced by this very research, ongoing oversight investigations and assessments of conditions of children within their programs, in government shelters, and within their communities throughout Tanzania. As an organization, they demonstrate ongoing evaluation of the situation within the country and within their own programming. From an upstream, critical perspective, the tensions that have resulted post-holding centre implementation is a direct result of, first and foremost, vicious human rights violations against persons with albinism: not the government response or any other NGO response since. The pieces that the government and NGOs have had to pick up as a direct result of violent attacks rests solely in the hands of those who would perpetrate and perpetuate such violence, not those who seek to ensure safety. That said, determining and committing to a way forward remains vital for all stakeholders as families continue to experience the aftermath of such trauma years later, noting too that families still experience fear and threats of violence.

While told in further detail in the last section of this chapter, Tishala's experience discovering that her children had been sponsored from a government holding centre provides a narrative highlighting the very tensions described above. Tishala explained how she had placed her two sons in a holding centre for safety due to violent attacks near their home. She visited them regularly once or twice a month and planned to bring them home as soon as the situation was safer. She explained how she first heard of children being sponsored by an NGO (*NGO-1*) on the local news channel. On her next visit, she arrived at the holding centre to be told that her own children had been sponsored and were now living at a boarding school about two hours away. Confused and eager to see her children, she struggled to locate the school; in her words, "I was sent to three different places trying to find the right school." She attempted again on another day, found the school, but was turned away at the gate: "I came and found the school…the school said, 'no, you can't see your children today because it's not visiting day.' " It is not difficult to imagine the pain and frustration that Tishala must have felt that day as mother and guardian of her children. She continued to explain what felt like a loss of her parenting rights without consent. When viewed through the lens of the chaotic, crisis response at the time, this story is representative of the sequelae of incomplete documentation and transition to sponsorship. Years later, she recognizes the opportunity for her children and reflects back on sponsorship with positivity while recommending clearer communication and parent involvement as sponsorships continue.

Boarding schools hosting children with albinism must be extra vigilant to ensure their safety. Fears around being accused or held accountable for any violence or apprehensions of children with albinism in their care remains a key concern and is a barrier to mothers accessing

their children and information regarding their children. This fear-based barrier to accessing their children must be addressed from a policy and human rights perspective and is further discussed in the next section as well as in Chapter Seven.

Another aspect noted by the mothers related to siblings with albinism. As highlighted in Imara's narrative in Chapter Four, parenting multiple children with albinism in Tanzania is burdensome. Sponsorship represents the potential of reprieve: safety, education, and financial aid. However, when not all children in the same family with albinism are sponsored, concerns around equity in the same household arise. Imara's story narrates the experience of parenting around and between sponsorship when multiple children in the home are impacted. Further, Oyana and Tishala affirmed a move towards family sponsorship regardless of whether there was more than one child with albinism in the family, stating,

> …[T]he mother is the same mother. How you separate children, it's not proper…we are the same mothers to all the children, when you support me it's not like you're supporting just me and the child with albinism. It is me and all my other children.

While understandably organization finances are limited, a model of family sponsorship versus individual child sponsorship could be something to consider, particularly in a culture where family is so central (Hudson-Weems, 2019). This proposed model of sponsorship will also be further discussed in Chapters Seven and Eight.

Parenting: Agency and Choice

While sponsorship has brought much relief to families impacted by albinism in the form of safety and security, financial support, and the provision of education otherwise unattainable for these families, a parallel experience has also existed. As I started to outline above, alongside

the relief and gratitude is the pain of separation from their children and the loss of parenting in the everyday. When the reason behind their need for sponsorship is their very right to life and security of person, this represents yet another (non)choice faced by mothers. In several interviews, the concepts of agency and choice were embedded within narratives. Removing the essential elements of parenting is disempowering. In an interview with one of the head teachers at a *NGO-1* partner boarding school, Maneno, articulated barriers to accessing their children and the loss of parental contact as experienced by the young girls in his classes. He discussed the bureaucratic steps that mothers must pass through prior to visiting their children or bringing them home for the holidays.

Boarding schools hosting grantees of *NGO-1* are in a difficult position. Operating in a society where persons with albinism are still at risk of attack and apprehension, those charged with providing care to children with albinism, family, or neighbors have expressed fears of being falsely accused of attacks or kidnappings or of being held responsible should an attack occur. In isolation of other details, such fear seems logical. With law enforcement charged by the government to crack down on perpetrators within a historically inefficient and unjust legal system, false accusations could occur. However, such fears are not occurring in isolation. Mothers trying to visit their children or keep in contact with them while they are in particular boarding schools[4] detailed various, costly, and frustrating barriers that they face to access their own children—who may have been sponsored initially without their knowledge (see above

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[4] From my understanding, the process described here does not apply to every boarding school or holding centre, rather some within particular regions where attacks have been higher or more recent. The policy appears to be site specific and not *NGO-1* mandated. The encouragement here is for an NGO-wide response that would mitigate the barriers caused by the process.

discussion related to government and NGO crisis responses). Echoing Imara's experience in Chapter Four, mothers and key informants interviewed in the Lake Zone region of Mwanza explained that in order to visit their children sponsored at various boarding schools, they must first approach their Street Leader for a letter confirming that they are indeed the mother of the child. They then must present this letter to the Ward Officer, obtain another letter of certification, and then finally to the District Leader who again certifies that the woman is who she says she is. These letters are then brought to the school for review and a visit is granted or denied. This process is prohibitive in that it is not only time-consuming, but also costly. Maneno (teacher and headmaster) detailed this same process within minutes of our interview following an initial question regarding his interactions with parents, specifically mothers, of the children with albinism attending his school. He too identified the process as prohibitive and excessive, but, acknowledged the reality in which the policy exists: Safety for their students is the priority and liability is a key concern.

In describing this process from the educators' and boarding school's perspective, Maneno proclaimed, "You see for them to know if you're the parent, that's the only way they can…I can't trust you because…this student they have come here through *NGO-1. That's the parent we know* [emphasis added]. You see now?" This statement validated the sentiment expressed by mothers interviewed: that they were no longer regarded as the parent, but had been usurped by *NGO-1* staff who held the information and ability to visit the children at any time. In conversation with *NGO-1* staff, this is certainly not the intention; however, very basic barriers to accessing their children such as cost of travel, loss of a day's (or more) work, other children to care for, and distance of boarding school from the home community is felt by mothers acutely.

NGO-1 does provide travel stipends to some families on an exception basis. However, the demand is much greater than the supply.

One mother, Jahaira, expressed a loss of agency in parenting following the sponsorship of her son. Her young son has attended boarding school since he was just over two-and-a-half years old because of continued threats to his safety. He has now been under the sponsorship program since 2014. Jahaira notes that he was recently moved to another school following a decision by *NGO-1* to relocate all grantees from a certain school. Likely affected by an overwhelming workload on the part of *NGO-1* staff in the area, Jahaira has been unable to determine what grade her son is currently in at the new school, stating, "So right now I'm very confused and not sure whether he is in grade one or in grade three." According to Waithera, placement exams are often completed upon entrance to a new school to determine the child's grade level. As Jahaira relayed her story, she was very emotional expressing her desire to know more about her child and how he was doing, tears streaming as she recounted how he didn't recognize her after his first month at the school. Her story further made the case for mothers to have easier access to and information regarding their children as well as the importance of communications between NGOs and families.

Summary of Storyline 4: Navigating Tensions of Sponsorship

Education sponsorship has provided many children with albinism the opportunity of a quality education from elementary school to graduate studies in university as well as safety and security above and beyond that provided in government holding centres. *NGO-1* and the programs they provide in Tanzania have filled a massive gap in services and resources available to persons impacted by albinism. Without their significant and ongoing response to the situation,

it is difficult to imagine what the current situation might look like. As with any service, reviews and program evaluations are important, something that *NGO-1* has acknowledged themselves and have been profoundly open to. This is a key strength of *NGO-1* as an organization. With a decrease in attacks and more NGO/CSO/government resources available, the sponsorship model may need to be evaluated, something the organization has noted. NGOs like *NGO-1* and *NGO-2* must be acknowledged as assets the government can continue to collaborate with in order to build services and resources meeting the needs of this particular population. In the long run, as local capacity is built, the possibility exists that NGO services may no longer be required, or at least not in their present form. In the meantime, however, *NGO-1* is in the process of reviewing their programs, restructuring, and responding to the findings in this research study and the broader project of which it is also a partner. That said, the findings of this study affirm *mothers as the key advocates for their children*. As mothers understand best the specific needs of their own children with albinism, they are in the prime position to advocate on their behalf. Indeed, a number of NGO staff with albinism recounted how their mothers were much of the reason behind their success in school and in life. Perhaps as mothers are empowered to play this role in their family, the strength of the parent-child bond is reinforced—despite such difficult, strenuous circumstances. The attacks have threatened to further disrupt the family unit: Services and resource providers are needed to prevent and mitigate this disruption.

Mothering: Resilience through the Life Stages of Parenting

With this final storyline, the preceding contextual themes are drawn together in a close examination of mothering, first by tracing the experience using a life stages framing, and second by elucidating the influencing factor of social support contributing to the possibility of resilience

for the mothers. The following section details the mothering experience from delivery,

postpartum, parenting in the preschool age to school age, and launching their children into young

adulthood. Each stage articulates the journey that I interpreted as one of survival to resilience.

These stories echo Imara's journey and highlight how slight differences can mean a complete

shift in the experience. This section also explores how this resilience is developed and influenced

by social and familial supports, most especially that of other women impacted by albinism.

Tracing Mothering through the Life Stages

From the moment her infant's pale, white head emerges from the birth canal, a mother's

life trajectory is in limbo. A mother delivering a child with albinism is at the mercy of those

closest to her: those assisting in the delivery (e.g., the healthcare team in the hospital, traditional

midwife, or family member in her home), her partner, family and relatives, and the broader

community. Their response will directly affect hers. If the healthcare providers or traditional

midwives are equipped to provide relevant, factual knowledge about albinism as a condition as

well as its genetic origin, she begins empowered—admittedly still vulnerable, but empowered. If

those who deliver her baby greet the child with fear, discrimination, and myth, their trajectory is

far more unstable. Mothers interviewed shared their experiences and provided stories that

expressed the full range of such responses—from complete rejection to acceptance.

Labor and delivery. The labor and delivery experience of mothers impacted by albinism

represents, perhaps, the most pivotal moment in the lives of women and their children. Women

whose babies are greeted with immediate stigma and discrimination instead of acceptance and

information begin a much more difficult journey from the outset. Further, women who

experience immediate stigma and discrimination are much less likely to enter the postpartum

phase with any useful information regarding albinism as a condition. Of the 17 mothers in this study who gave birth to a baby with albinism, 14 shared their delivery stories (those that did not were a part of sharing circles and while they agreed with their co-participants that delivery was difficult because of similar reasons, their stories were not explicitly recorded). Only three of these 14 women (~21%) narrated a positive experience. These positive experiences related only to how they felt treated upon delivery: Was the healthcare provider willing to touch her and her baby? Were they whispering to colleagues instead of talking to her directly? Did they run away or abandon her during delivery? Were they kind and attentive in any way? Not a single mother of the 17 interviewed left the hospital with education regarding albinism as a condition and what care needs her baby specifically had as a result. Important to recall here is the age range of children with albinism of the mothers interviewed (see Figure 7), that is, between six months of age and early thirties. Interestingly, the two women in the larger sample who delivered at home with a retired nurse (Jahaira) and a Catholic Sister (Magreth) both had positive experiences: The birth attendants were accepting of the baby and encouraging of the mother. However, similar to hospital experiences, neither mother left with knowledge regarding albinism. The following accounts detail experiences in the hospital and immediately after.

Mothers described hearing nurses whisper to each other, display expressions of shock and fear, literally run away and scream (e.g., Joyce and Oyana), refusing to touch the baby or assist with routine care measures (e.g., weigh, bathe, and dress the babe as in Asha's experience). Asha's experience was compounded by the fact that her nurse immediately helped the woman who delivered just after her, cutting the baby's cord and assessing the infant before returning to help Asha and her baby with albinism. The cord had not been cut, she had not yet delivered the

placenta, and her baby was not assessed. This immediate othering on the part of healthcare providers reinforces precisely what all of the women noted experiencing within their communities: accusations, rejection, fear, abandonment, and misunderstanding. Amana spoke of nurses in the delivery room accusing her of sleeping with a white man, and leaving the hospital with no specific health education as to how to care for her baby with albinism.

> The doctors were very curious, the nurses were asking, "are you sure you didn't sleep with a white man?" These kinds of questions. When my auntie came to see me in the hospital, she asked me the same [questions]. I was seen as very evil and promiscuous, they presumed I went out with a white man. The father didn't come to the hospital. He came to see the baby at home…and the minute he saw the child he said, "No, that can't be my child."

This rejection on the part of fathers, as noted in Chapter Two, the literature review, is very common with the delivery of a child with albinism. The ability to immediately deny paternity when the baby's skin color is so opposite their own makes this abandonment altogether too easy within the context of existing myths and beliefs. Not involving fathers of children with albinism in pre-discharge education regarding the birth of a child with albinism furthers this potential. The next section on early years will explore this theme more thoroughly.

Quite the opposite was Penda's account of her delivery and immediate postpartum period. Penda delivered on her own in her house while her partner was attempting to get her a ride to the hospital. Upon delivery, Penda notes that she herself was afraid of the baby, having no idea why she was white. Her husband, however, expressed the following upon seeing their daughter:

He took the baby and he said, "Wow! Today you've delivered a *muzungu*...in our family

there used to be these very light people and they were very beautiful. Now today you've

delivered another *muzungu*."

This story of initial acceptance by the baby's father versus the mother was the only example of

this within the broader study. With tears in her eyes, Penda gave much of the credit of their

child's success to her late husband who had only recently passed away. It was evident that his

support and commitment to continue providing for the entire family enabled their ability to thrive

together, ensuring the best possible care for their daughter with albinism as well. His

understanding of genetics through an African ontology, "in our family there used to be these very

light people," where family is central was echoed by other participant's older relatives who made

similar statements of acceptance. In Imara's story, for example, her mother in-law said, "this

child is my sister."

In an interview with a nurse and midwife, Sakina and Taraji, in the Lake Zone region,

there appeared to be a recent shift following education provided by TAS, done by persons with

albinism, to the staff at the hospital. Both participants applauded this education. The midwife,

Taraji, shared the following:

Taraji: She says she's actually had an experience with a mother in the hospital. They

counselled the mother and she accepted the baby. But, she could clearly see from the

family and relative that came that there's a problem and she didn't know how now to

support the mother post hospital. She also was not sure, when the child goes home if the

child is going to be safe or not…

R: And how is the response from…the rest of your team, from your nursing staff and the

doctors?

Taraji: She says for them, of course when they saw the baby first they all said, "Oh, you

have a white baby." Even for them they know as nurses if they show the shock then the

mother will also have been shocked by the same thing. So for them it's like they were all

happy and that's why you do follow up counselling now and then after…So they also

counselled the mother on taking care of the child and how to protect the skin and all that.

R: And was there, was that teaching done just with the mom or also with the father there,

any extended family?

Taraji: The culture here they don't come to the birth with their husbands. They come with

a female relative. So with this particular case they talked to the mother and her female

relative who was present. So she also counselled them against harmful traditional

practices and she even tried to find out if they have other people with albinism in the

family and when they said no she told them, maybe this mother carries the gene, the

albinism gene.

R: And did they seem to understand this concept of an albinism gene?

Taraji: They don't get it very well because you see they ask themselves, they don't have

albinism, they have this child.

This account from Taraji demonstrates how nurses are attempting to engage mothers and their

female relatives who come to the hospital with them. Both Sakina and Taraji described feeling

tension around not knowing how the mother and child would fare outside of the hospital, but

expressed relief in attempting to connect them with the district social worker and ensure they are

aware of when to return to the hospital clinic for routine care (e.g., vaccines). These routine visits would also include albinism education—something that is now more broadly implemented in this particular hospital. When driving to this interview, the *NGO-1* staff described this hospital as a key provider of albinism-related services in the area, praising their recent efforts to ensure excellence in albinism care. Clearly more hospitals and clinics that share this interest and commitment to lead the way in albinism care, collaborating and sharing best practices, will benefit the albinism community as a whole.

In a debrief conversation with Waithera following one of the sharing circles with women in the mamas' group, she asserted the following:

It starts in the labour room. I keep saying that…that is the first place where a mother is told "it's a girl/it's a boy." That is the place where everything else should be very clear: "it's a boy with albinism and ABCD."…If we don't solve it in the delivery room, we will not solve it in school.

This opportunity in the delivery room and maternity ward immediately following delivery represents the prime timeframe to connect mothers with key resources and information. It was encouraging to hear Sakina and Taraji, nurse and midwife in Mwanza region, describe the albinism education their hospital and staff had recently received from persons with albinism. They noted that there is currently a focus on ensuring nursing staff have the knowledge and appropriate care for mothers impacted by albinism along with prioritizing social services for these families prior to discharge. Further investigation into how widespread this type of education for healthcare professionals and staff is nationally would be a helpful indicator of the level of uptake and potential for accomplishing what Waithera is calling for.

Figure 10. Delivery room in a rural hospital. There were three beds in a row, separated by the curtain dividers. Photos such as this illustrate the proximity of women delivering, providing context for Asha's story.

Postpartum and parenting in the early years. The postpartum period directly following this central experience of delivering their baby with albinism is rife with fresh challenges. With little time to process her own shock and feelings around having a child that looks so different from herself, a mother now faces the response of her spouse, family, and community less than 24 hours after delivery (typical timeframe of hospital discharge per interviews with nurses and midwives). In a culture where women surround and support their fellow postpartum woman in very practical ways (e.g., cooking, cleaning, helping with childminding), this help disappeared for the majority of mothers interviewed. Instead, mothers faced isolation, questions, and

accusations—their babies a spectacle in the community. As alluded to above, partners/spouses abandon mothers who deliver a child(ren) with albinism at alarming rates. As in Imara's story, sometimes fathers seek another wife to produce "normal" children for him, while remaining an unsupportive and, sometimes, violent and abusive presence in their family because of his beliefs around albinism. As mentioned previously, for Amana, her child's father simply denied paternity, leaving her in a position to parent alone. Knowing that she needed support, she brought the situation to her brother in-law:

> Amana approached her brother-in-law and he said they will call a family meeting to discuss the issue. In that meeting this guy who had fathered her child said in front of the brother, "no, I have never had sex with this woman"….After this meeting she never again made an effort to reach out to the husband's family. Instead of that whole fight, she decided to be on her own as she's always been and raise the child alone.

Amana was well acquainted with figuring out how to support herself and instead of enduring more scrutiny, baseless accusations, and impossible demands for proof, she dropped the issue. As an orphan growing up with extended family, she had had to fight for her own survival already. This did not appear to be any different.

Tishala's experience was similar. However, her in-laws sought to excommunicate her from the family. Here, she describes delivering their second child with albinism:

> When the second child was born with albinism...the father was the saddest man. He went back home and they asked, "What baby has been born?" He said, "Ah, the same type of kids that she delivers." So, when now they went back home it started the back and forth of family meetings and same things, trying to excommunicate her because "she's not a

woman enough and we can't continue keeping her; she's just defiling our lineage; she's

not a woman enough, she can't deliver proper kids…" Eventually, they took her back to

her parent's home.

Perhaps most difficult to grasp is this accusation of "not being woman enough" by delivering a

child that is perceived as "other." As will be further described in Chapter Six, Hudson-Weems'

(2019) theoretical framework of Africana Womanism notes how central family and childbearing

is to the African woman's experience and existence. So much of her value lies in her nurturing of

a family. One imagines that being accused of failing to do this "successfully" would be

devastating to any woman. However, the resolve of both Amana and Tishala, indeed of all the

mothers interviewed, to move forward with their child(ren) exemplify the tenacity and resilience

that mothers require daily in choosing to raise their children with albinism.

As researcher, it was fascinating to hear mothers explain strategies to convince their

partners or family to accept them and their child(ren) with albinism. The creativity required is

astounding. For Akina she describes her husband being "really shocked and then later was fine.

Today they are very together and they do everything collectively." Having not heard this kind of

shift before, I asked, "And what do you think changed for your husband. He was shocked at first

but then what changed?" Her response was clever:

So the husband's [family], when they come they are very, very fair. It's only hair that is

black. So for her even if she knew nothing about albinism she told him "you see, look at

your family. You are all very fair so it is very clear that this really came from your end."

And that's how he somehow got convinced.

As demonstrated, getting their partner on board appears to be the most important factor in the early stages. Because it is so easy for men to blame their wives as the one whose body forms and delivers their child, getting him to recognize "that this really came from your end" is an important method (Akina). While genetics are not widely understood from a biomedical viewpoint, the idea of lineage and bloodline is. The ability to point to either a relative who had albinism or the delivery of "very fair" babies on the father's side would open the possibility of this child being *theirs*, not only *hers*.

Of the 17 women interviewed who had children with albinism, only 41% of fathers represented in this study (that is 7 partners of the 17 women interviewed who have children with albinism) stayed, representing various levels of involvement and support, from fully invested, to barely acknowledging their child with albinism. When facing poverty and the lack of resources, even minimal amounts of support make a meaningful impact. Regardless, these men are the exception. Russom's husband not only stayed, but accepted his daughter with albinism. This embracing left him in a position to defend his daughter and wife in his community:

> So you know now because people were still talking in the neighborhood and the husband goes out to drink. So every time he would get into fights with people because they are trying to tell those lies and stuff like that, he was very defensive you know because he already accepted this child and people tried to convince him otherwise. So he would come back home and tell her a warning. "The way people are talking here you have to be very protective of the child because we do not know the good and the bad people here." So made the resolve that her child would only be seen either when she goes to church or when she goes to clinic. So she locked the baby in. Even with the clinic, she spoke with

the nurses and told them, "me and my child will be coming in the afternoon when there

are no crowds of people. So because it's hard for me to already differentiate who is the

good person in the crowd and who is a bad person…"

Russom made the decision to "lock the baby in" her house for protection. As a teacher herself

and needing the income, she had to navigate how to manage keeping her child safe while being

away at work, as observed in Imara's story. She goes on to describe trying to hire security guards

to help keep her safe, but they were not trustworthy. This difficulty to "differentiate who is the

good person in the crowd and who is a bad person" highlights the level of alert that these

mothers must be on at all times. Russom describes how her daughter was born at a time when

violence against and killings of persons with albinism were on the rise. Her fear was based on

current events. Her solution was as follows:

> …[N]obody she could trust and nobody she could get to take care of the child, she
>
> decided to start going everywhere with her child when she was as young as three years…
>
> she would go to teach with the child. She would spread a blanket next to her and teach
>
> other kids when the baby was there.

Russom was lucky to find support in the head teacher at the school she taught at. This head

teacher advocated for Russom, requesting that her colleagues have patience and grace with her,

noting the difficulties for families with children with albinism in Tanzania at the time. She

requested that as a team they make adjustments to support Russom at work. However, Russom

articulated the sacrifices made in bringing her daughter to work in part by stating, "she realized

the baby would be so tired at the end [of the work day]…even productive wise and workwise she

started noting it was affecting her output. And, of course, the way the baby was also suffering

too." These tensions were a direct result of the risk of violence that persons with albinism face in Tanzania, especially during that time and is, again, representative of the (non)choices experienced by women impacted.

These early years were also illustrated as confusing in terms of caring for the health of their young child with albinism. With not a single mother entering the postpartum period knowing what albinism is and the healthcare implications, each of them described a period of trial and error, eventually, sometimes not until the child was much older, receiving some level of health knowledge from an HCP. This encounter, however, was most often coincidental, meaning that mothers were bringing their children to a physician for a different purpose or were approached by an HCP or organization themselves. Prior to these more formal encounters, many of these mothers talked about utilizing traditional knowledge shared in their communities, such as applying various oils to their child's skin for protection and realizing that their skin burned when in the sun. Tishala's experience highlights this stage and echoes the experiences of a number of other mothers interviewed:

> [W]hen raising the child…most of the time she just applied the regular lotion. And then she noticed [he had] irritations on his skin, so she decided to use the cooking oil. She would boil the cooking oil and then let it cool, then apply. But even then he started getting sores on his head that had pus…So they would break [antibiotic] capsules and put the capsule powder on his wounds cause they were really bad… she said that one would heal and then the other one [would appear]. So around that time some people called them to a meeting…someone called and they were educated on albinism in 2007 and it is in

that place they were told like you should go to [city hospital] to collect sunscreen.

There's someone who provides sunscreen there for such kids…[He was] six.

Eventually, all of the mothers interviewed had an interaction with a physician or

organization that recognized the condition as albinism and provided education and sunscreen to

them. However, this rarely seemed to include education related to vision and eye care. As

confirmed by Oyana, who did not receive such education until her son was seven years old, "No,

the doctor just talked about the skin care and nothing about the eyes." With now well-established

organizations like *NGO-2*, these experiences are shifting with the increase in mobile clinics and

organizations working together and alongside local authorities to identify new families impacted

and provide early access to education and health resources.

Parenting through the school years. These early years are representative of a number of

initial challenges that mothers with children who have albinism face. However, the challenge of

education and parenting their children throughout these school ages brings fresh obstacles.

Mothers become key advocates for their children as they enter spaces where acceptance has been

the exception and not the rule. Most of their children experienced teachers who misunderstood

their condition entirely, forcing them to play outside under the sun, not understanding their low

vision, and/or failing to provide safe spaces socially and intellectually for them to learn. Not only

are their children undergoing the typical developmental stages/milestones from school entry to

young adulthood, but they are navigating a society that has not understood them and still does

not quite know how to include them. According to stakeholder interviews, focused campaigns to

provide albinism-specific education to teachers throughout Tanzania is hopefully beginning to

shift teachers' perspectives as they become more aware of the specific health and vision requirements for their affected students.

The first concern at school age voiced by mothers was how to ensure the safety and security of their child(ren) while at school and in transit to and from. The next worry was about how to pay school fees for their children, regardless of school choice (i.e., government day school or boarding school). Recognizing that most of the participants in this study have children who entered school during tenuous times in terms of violence against persons with albinism in Tanzania, an alternative to day school where safety was not guaranteed was to bring their child to one of the government holding centres which functioned as a boarding school. This alternative represented a difficult choice: near guarantee of safety but separation from parents and family. Bringing their children was a sacrifice and, for the mothers in this study, had nothing to do with not wanting to parent their child(ren) with albinism; rather, it had everything to do with navigating raising a family and ensuring safety and security for their child(ren). Mothers articulated countless ways in which they explored creative pathways to keeping their children safe while trying to ensure they receive an education. Of note, mothers recognized "quality education" as the key to their children getting out from under the oppression and discrimination they experience, as well as the gateway out of poverty.

As described in Chapter Four, Imara's explanation of bringing her daughter to a "special" school for children who are blind and/or deaf in the hopes of ensuring safety and a more catered education to her particular needs highlights how mothers advocate for their children. Further, her case also emphasizes the impact when not all children with albinism within a family are sponsored by the NGO to attend this "quality" education. For Imara, the experience of parenting

one child sponsored by *NGO-1* and two other daughters with albinism not under sponsorship highlighted an important tension to consider regarding siblings, one that needs further study. Her difficulties finding a suitable school and making the payments were also echoed by other participants.

Russom, as a teacher herself, explained how she navigated first bringing her daughter as a toddler to work with her to ensure her safety and then bringing her to attend this very school herself once school age for the same reason. She notes that because her daughter had become so used to being in that environment, playing and interacting with the students, the transition to becoming a student was very difficult for her. "It was very hard for her to differentiate when it's learning, that transition. There was no home to school because school was home for her." Russom described her daughter trying to find her during class time, disrupting her own class and other classes in the school to do so. During one particular incident, this disruption resulted in her daughter's teacher sending her to stand outside as punishment. This was despite Russom attempting to inform her daughter's teachers about her condition (e.g., sitting at the front of the classroom, not being in the sun). Struggling to determine a way forward that would be safe for her daughter and ensure she could maintain her own job, she trialed sending her daughter to another school close by. However, for safety, she had to walk her daughter to and from school every day—something that required her to be late to her own classroom some days. Her husband soon lost his job and paying for school fees became a serious struggle. There were times that the school would simply send her daughter home mid-school day by herself without alerting her or her husband. Russom stated how "she worried that if anything happens to her this time she's sent unaware then where does she start? So she talks to the school but it doesn't seem they get that

point." Further, her daughter is very "outgoing and a friend to everybody." She says, "Of course as a parent you would not trust people. Still you have to still be protective because as much as we think things are better the violations are still going on." The solution for Russom is to attempt to earn more of an income to support her family—2 children in university, 2 in secondary school, and her young daughter with albinism in primary school—in the hopes of eventually being able to send her daughter to a quality boarding school. On top of her teaching job, the mamas' group she is a part of has taught her how to make soap, providing an extra source of income:

> …Now she says for sure the soap making… gets some little money that helps her get the daughter going for the next day. And also the income they get from this group somehow pushes it. Of course it's not enough… everybody is still getting a share from this little income that she has.

To this point about earning more of an income, this is directly related to the support of NGOs making *Wamama Wanaojali* possible. Russom, however, stated that even with this support and "economic empowerment…the support is still not sufficient because they still have…routine needs…they're not [solved] today and tomorrow you don't need [again]…but they are still grateful for the support that they get."

For Amana, "her biggest thing, of course, is the daughter has no access to that quality education," echoing that of mothers whose children are not currently in a sponsorship program or able to afford sending their children with albinism to boarding school. This comment was made during the first visit to Tanzania for fieldwork. In the follow-up visit, I was able to connect with Amana again. She reiterated her desire to see her daughter in a safer school where she could receive a quality education. To this point, Amana shared their recent experience of a kidnapping

attempt as her daughter was approaching school one morning. After walking her nearly all the way to school with her daughter, as she does daily, she waved goodbye a few blocks away and rushed to her own job. During this particular day, a man was waiting outside the school, approached her daughter, and attempted to lure her into his car. Thankfully, a teacher spotted her daughter and ran outside to call her name, interrupting the attempt. Amana was immediately called to come back to the school. For Amana, the exhaustion and terror of being on constant alert, even when she is quite sure her daughter is in safe hands, appears to be overwhelming. Trying to earn an income to support the rest of her family while balancing having to monitor her daughter's safety so closely poses a near-impossible task. Importantly, this attempt occurred in 2019—meaning that risks and concerns related to safety are indeed *current*. Amana describes this anxiety and stress here:

> And even for her, if she didn't have to take the child morning and evening to school, she can't even manage to look for a job that is a working job because she has to somehow be there for the child to take them to school and bring her back. They struggle a day at a time…And now that she's going to just a regular school she practically has to take the daughter, wait nearby until the school is over to take the daughter home.

On top of physical safety concerns, her daughter is also facing bullying and discrimination in the school. Amana describes how "the kids in the school are so, are very discriminating. Sometimes they take her glasses, they take her shoes. Like she can see a lot of stigma. So she's really not sure of the safety of her child."

As referenced in the previous section on mother's experiences of sponsorship, Tishala's experience of placing her sons in a government holding centre followed by an NGO sponsoring

both of them to attend private boarding schools illustrates the complicated nature of parenting during this time in the Tanzanian context. The following expounds on Tishala's experience after locating the boarding school they were sponsored to attend. She went on to tell Waithera and I that her youngest son became ill quite soon after he had moved to the boarding school and was hospitalized, without her knowing. He died in the hospital without his mother knowing of his illness. She learnt of his death from her estranged husband. Surprised to hear from him then at all, she thought he was playing a cruel joke on her by giving her such news. To investigate herself, she phoned the guard at the holding centre whom she had become close with throughout her children's time living there. She said from the moment he answered the phone she knew her son was gone: "Oh, Mama Jabori. We are so sorry about the loss of your child." Her pain and confusion is captured in her questions: "how can this be? Why did they even know when my child got sick, why nobody cared to inform me and tell me so because [I am not too far]? I have gone there many times looking for my children. Why did nobody call me and tell me to come take care of my child?'" She wonders about litigation, but sees that as adding pain. She shares her traumatic story with us with the hope of change: "[I] pray that, yes, my story should be used to make sure any other mother or parent [doesn't] go through what I went through… I wish it is me who saw him die rather than someone else because then all this being told I still have so many questions that are not answered." This loss is offset in part by the success of her older son, who stayed in the boarding school and now, nearly ten years later, has just graduated from high school and has plans to attend post-secondary education. Her huge smile as she told us about his achievements told us how proud she is of her son. Somehow she seemed able to hold in one hand

the terrible tragedy of losing the younger son and in the other celebrate with gratitude the success

and opportunity that the remaining son has experienced.

Russom and Tishala's stories highlight the tensions and (non)choices that these mothers

face as well as the consequences of the dire human rights situation in Tanzania during this time

and the resulting responses launched to provide support. School age brings complications.

Mothers are faced with how to ensure their children are safe and secure when they are out of

their sight—balancing ensuring they are in school safely with having to work odd hours and

away from them in order to pay the school fees (e.g., gathering fruit to sell on a street stand as in

Imara's description). They have to advocate on behalf of their children, often not knowing much

about albinism themselves in order to do so adequately.

Transition into young adulthood. Mothers recognized quality education as the key

necessity for their children with albinism to make a way for themselves in the future. This was

true for mothers whose children were currently under a sponsorship program as well as those

who were struggling to pay school fees for government day school. Of note, President Magufuli

introduced fee-free basic education policy for primary education in 2016 (Ministry of Science,

Education, and Technology Tanzania, 2018). This policy change is a promising shift towards

achieving their ambitious 2014 Education and Training policy outlining key education goals to

be reached by 2025 (Human Rights Watch, 2017; Ministry of Science, Education, and

Technology Tanzania, 2018). However, while outside the bounds of this current study, the

discrepancy between this policy and stated family experiences of still struggling to pay school

fees raises questions and needs to be further assessed. This lack of access to safe, quality

education was a key barrier in participants' children successfully completing primary school. To

this point, for children of participants transitioning from school age to young adulthood, whether returning home or proceeding on to post-secondary education, success was dependent upon experiencing this access either via parents or sponsorship from an NGO. It is helpful to set up the current state of education within Tanzania, based on percentages or numbers of students attending primary, secondary and post-secondary education within Tanzania (recognizing that these numbers do not differentiate based on geographical location). Data from the Ministry of Science, Education, and Technology Tanzania (2016) cites that primary school net enrolment was 84% with "more than 70% of the primary school leavers transit[ing] to secondary education" (p. 3). Post-secondary attendees have "more than quadrupl[ed] over the past decade" with 40,000 in 2005 to approximately 200,000 in 2015 (p. 3). While these numbers are encouraging, these statistics do not include students with disabilities. In the same document, the Ministry of Science, Education, and Technology (2016) offers a critique of the current system. With an estimated 400,000 school-aged children with disabilities, "47,783 children are registered in primary and 8,778 in secondary schools. This leaves a large out-of-school population of the most vulnerable children" (p. 38). Named in the list of disabilities considered, albinism appears first. With a commitment to include questions related to albinism on national censuses, statistics regarding education could be more specifically tracked in the future.

Within the broader study of 26 mothers interviewed, four mothers interviewed have children either close to secondary school completion or recently graduated, while six mothers had children already in or graduated from post-secondary education. These mothers expressed hopes and concerns around how they would now transition back home, to a workplace, or to university. Comments were made about marriage and family, earning an income, and qualifying

for post-secondary education or trade/vocational school. Comments were related to ensuring that

their now-grown children with albinism would be able to transition well into adulthood. Mothers

spoke of encouraging their children to focus on their studies in such a way that guarantees future

employment and the ability to provide for themselves. As a grantee of *NGO-1*, the NGO

commits to funding education from start to finish—including as much education as they would

like to do and qualify for. Mothers like Jiona spoke with great pride as she shared that her son

was now in university, stating the following:

> Yes, he's in the University of Dar es Salaam…the community was amused because…
>
> every person who gives birth to a child [who is] different, there's always whispers and
>
> talks around the community. But now, [my] son has this personality that is so, he's very
>
> social and interactive and somehow walks around it.

This idea that her son "somehow walks around it" speaks to the resilience that her son has—

empowered to exist fully regardless of stigma, something that Jiona surely helped to instill in

him: "She says she gives him the love of everybody that he never got from everybody…there

was no debate: he is her child and she can take care of [him] without depending on anyone."

Tishala's son was in his last semester of secondary school when I interviewed her. While

so proud of him, she was concerned about him moving home for the summer as he waited to

determine if he was going to university or a trade program. With her one-room home, she was

worried what it would be like for him living with her and his younger half-siblings after being in

a boarding school for most of his school years. She was unsure if she could manage providing for

the whole family and assist him to prepare for life after secondary school.

Imara voiced struggling to see Aisha fully trained as a seamstress but unable to find consistent work. While trained as a seamstress, Aisha received no formal training in how to start a business of her own. She has had no luck getting hired by other dressmaking shops. Currently, she is now living at home with Imara, helping with her younger siblings and relying on word of mouth from the *Wamama Wanaojali* group to take custom sewing orders.

In a post-interview debrief with three NGO/CSO staff, including Waithera, after the interview with Kamaria in a remote, rural setting, one of the CSO staff made an important comment related to the differences between men and women with albinism. He said that for a man, safety remains a concern, but he has an ability to fight back and assert himself in various ways in life that will serve as a protective mechanism, including marriage. All three of them agreed that for a man with albinism, marriage does not pose a risk. They have the ability to choose whom to marry and maintain the status of male provider in their homes. For women with albinism, however, relationship and marriage actually poses a risk:

> ...[T]he security for men is not so much a problem. But for women the situation is terrible. Why? Because women are easily cheated by men…they do come for…getting married…it is very difficult for the woman to know that this is really, is meant for me to be his wife…

It is on this point that data from mothers *with* albinism themselves interviewed in the broader study have informed my interpretation in terms of what mothers of daughters with albinism are trying or will be trying to help their daughters confront about the experience of women with albinism. For Zahara, a mother with albinism herself, she was with a man for a number of years—he fathered all three of her children, all without albinism. Zahara looked down as she

said, "He left me when I had the three kids and married another woman who is educated and not a person with albinism." She has since been raising her three children with no support from him in any form. Living with her sister and her husband has brought several challenges as she feels like a burden to them and feels aware that her brother-in-law does not wish to continue sharing a home with her. As a woman with albinism she shared poignant insights describing the various barriers she must navigate because of her society's false beliefs about albinism. She talked about her community members' belief that people with albinism aren't capable of anything: "you can't do this, you can't do that…'you can't cook,' 'this one cannot even give birth.'" She described how deflating this is to one's sense of self. Further, as a woman with albinism she talked about how men are curious "how is she?" Explaining that they want to know "how is she to sleep with?...So they will come try getting into a relationship with you…and you accept that. They will sleep with you [and] go tell others." Here she expressed the impact on your dignity as the gossip spreads around your community: "you see from the beginning they were just coming to see how you are…So even as you walk, people know how you are—your dignity is shattered." Zahara recounted how she felt dismissed regardless of how she attempted to support herself and her children.

> So you see even when you get out of the house and want to really make ends meet [like] any other mother, you will go out there, they will do all those things to you, they will say all those things to you, you have the business, you have the brain, you have the idea and you are out there trying to do it but they won't even buy from you. You see? So as much as you try to improve yourself, first your dignity was already shattered…at the end of the day you become this person who tries everything and succeeds in nothing…And that's

how you find our lives as women with albinism are very miserable because then you're

discriminated at all levels...

As a woman in her thirties, Zahara is well aware of the challenges a woman in her position faces,

particularly when she has had little opportunity to pursue her own education. The picture she

illustrates is bleak and unadorned. Her reality is one that she and her fellow mothers in the

mamas' group are trying to shift for future generations. Zahara went on to discuss in the

interview how her dignity has been elevated once again because of her participation in the

mamas' groups and the opportunities it has provided her. Mothers raising daughters with

albinism in the *Wamama Wanaojali* and other mothers' groups benefit from shared experiences

such as this. One of the mothers with albinism, Goma, when I asked if the group would prefer to

interview separately as women with albinism and mothers of children with albinism, declared,

"you are our mothers and we are your children," indicating their desire to share together. Further

discussion about the impact of these mamas' groups is presented below.

Survival to Resilience: The Impact of Spiritual and Social Support

For many of the mothers interviewed, poverty and the struggle to provide for themselves

and their families was already a part of their personal narrative: Women are surviving from one

day to the next. Once they delivered their first child with albinism, the intersectional experience

of being a woman, confronting poverty, abandoned by their partner, and having a child with a

disability compounds their lived experience. Various (non)choices were experienced by all of the

mothers interviewed, in one way or another. Of the 26 mothers interviewed in the broader study,

24 of them (92%) experienced precarity and struggled to provide basic necessities for their

families. Amana noted, "I'll do all the odd jobs that I can do to raise this child." She continued,

"That is really how our life is right now. If we have food for the day, fine. If we don't, fine…"

Mothers with this story, however, know how to survive in large part because survival was not

new for them. Their stories depict the journey from survival towards resilience, particularly

when they encountered resources that supported their efforts in raising their children who face

stigma, discrimination, and risks to their health and well-being. This next section considers this

possibility of resilience: What did mothers express as empowering, capacity building, and

helpful supports? Their will and perseverance to survive and raise their children was clear, but a

shift from survival to resilience was evident in reflections on "joining hands with others to be

able to raise her child and not feel like she is alone" (Asha). Several excerpts from participant

interviews already outlined in previous sections illustrate how mothers move from surviving in

their everyday to experiencing empowerment and the capacity building of faith and social

support networks like the mamas' groups mentioned previously.

  Spiritual support. Faith and spirituality were themes that appeared in the majority of the

interviews, at the least as an explanation for receiving such a child as "God's will" and "a gift

from God." A sense that "this is what God gave me, therefore I will love this child." Oyana's

statement articulates this finding well in response to the general question regarding what she

identifies as key supports in her life:

> My biggest source of support is God because I know, I know God provides. And here I
>
> make some income in the [mamas] group so when I make that income I will at least go
>
> buy food and support my kids where the father doesn't.

As will be discussed further in Chapter Six, this deeply rooted sense of the spiritual and belief in

God is common in an African ontology and is representative of how one's life is explained and

made sense of. Regardless, for women with few supports, the manner in which they expressed their faith in a kind, accepting, loving God who acts as protector and sustainer represents one of the building blocks towards their resilience. Instilled with a sense of hope, where their belief in a God that welcomes them into "His" family stood in direct contrast to the alternative reality of ostracism and discrimination. Further, that this God is all-accepting and the Creator of the child central to their abandonment gives the purpose and meaning to their existence that society attempts or threatens to remove.

Also under this subplot of spiritual support is the nature of the women's groups. Two of the groups exist in large part because of the support and initiation of a faith-based NGO and its staff. From my fieldwork, including participant observation, the groups made time for prayer and fellowship together, including reading scripture from the Bible together. Mothers spoke of this time as encouraging and providing a sense of hope. Interestingly, few mothers spoke of being involved in a church or mosque community outside of this group. Instead, they mentioned occasionally seeking prayer with a pastor or going to mosque to pray—both actions described as comforting and an opportunity to ask for help from a higher power. The potential role of faith communities is further discussed in Chapter Seven.

Social support. Within many of the narratives, mothers expressed support coming from unlikely places. Oyana spoke of the uncommon juxtaposition between the "stigma, discrimination, teasing…and rejection" from her family alongside her neighbors "encouraging her to raise the child." While Oyana had support from her neighbours, she did not have support from her family. Oyana's, journey also echoes that of other women, including Imara, when she spoke of her husband's grandfather as the only supportive family member. For Imara, as outlined

in Chapter Four, she received support from her mother-in-law only after another elder in the family identified albinism in their lineage. Further, four mothers (of 17 without albinism in the broader study) remarried after partners left them and their children. These second marriages were described as very supportive, loving, and protective. It is curious to consider what would motivate a man to leave his own child but enable a man to take on a child with albinism as if they were his own flesh and blood. Future studies would do well to investigate this angle of the gendered dynamic of albinism. Regardless, support from these second marriages or subsequent relationships offered support not identified elsewhere. Oyana highlights the contrast of her second husband in the following excerpt from her story.

> She married her second husband and with this husband she got another child who didn't have albinism. They lived with the man for seven years but then he eventually passed on…He married her together with the child. This man was very loving, the one who passed on. And he loved them, never discriminated...even when he goes shopping he would buy stuff for the two of them. He was very, very loving to the children.

That something as essential as "buy[ing] stuff for the two of them" would feel so counter to how her previous spouse treated her and her child with albinism exemplifies the inhumane conditions families are facing. That such basic support strikes such a contrast and makes an immense difference suggests the wide spectrum of support needed, that seemingly small or minor acts set into motion a shift in everyday life.

Asha expressed a sense of support from her older siblings who also have grown children with albinism. She noted that, though her husband left her and their child with albinism immediately upon delivery, the comradery she feels with her siblings who have grown daughters

with the condition has caused her to feel less alone. As Waithera translated, "every need she has, she turns back to her siblings…she went to see [her brother] and he [said] there are other children like [yours] somewhere…It is nice for her to join hands with others to be able to raise her child and feel like she's not alone." Looking around at the table at the group of women, Asha said, "You, you are also my family, eh? You are also my family." What is important about the support of Asha's siblings is that while in the Tanzanian context the typical source of support would be from one's husband and in-laws, where one's own family of origin is less involved after marriage, in this case, it is her own siblings who are key supports for her. Again, support arrived from atypical sources and was well received regardless.

More extreme are the ways in which neighbors and community members intercepted kidnappings and violent attacks. As mentioned in previous excerpts throughout this chapter, neighbors and Street Leaders were noted as being responsible for intervening at key moments. Mothers noted this support as enabling them to feel some sense of security and support in their homes and neighborhoods—knowing that their community members were looking out for their children and willing to literally blow the whistle for help to arrive. This community capacity has developed over the years with engagement by various NGOs in educating community leadership as to what albinism is and the key concerns that families impacted by the condition face.

Sisterhood: Other women impacted by albinism. Much has been said in this chapter about the vital role of the mamas' groups. From the interviews, it was clear that relationships with other mothers impacted by albinism altered their sense of support radically. Having other women in their lives that have experienced much of the same stigma, abandonment, threats of violence, and struggle to provide for their families was discussed as a relief, a remedy to the

loneliness. Statements such as "I have no other place except the group," "this connection keeps me going," and the sense of "hope I get from this group" each explain how pivotal these connections are. That the bond between women similarly impacted by albinism makes such a difference in their lives is representative of the level of loneliness and isolation that mothers in this study experience as a matter of their everyday lives. Beyond the psychosocial support found in these groups is the opportunity to earn an income based on the small enterprises these groups have formed. Beyond connecting socially, they identified learning skills such as soap making, beeswax wraps, candle making, and sewing, as well as communication and customer service experience. Echoing various participants, Jiona stated in response to the question related to her main challenges in raising a child with albinism, "My biggest challenge either way is capital so that I am able to build on myself without worrying about literally putting food on the table." Quite brilliantly, the mothers' groups currently formed within these NGOs address the social alongside the economic—arguably any model would have to do just this.

> We all have small, small businesses. And these businesses of course are not sufficient.
> But I know there is power in groups. (Goma)

Mothers' and stakeholders' views on resilience. The concern is whether the approach to resilience in this study inadvertently embraces a Western understanding of the concept. While I saw these women as incredibly strong, facing remarkable odds, the remaining question was what a Tanzanian interpretation of resilience looks like. As part of my interpretation phase, during a second field visit, I spoke with several of the mothers and key stakeholders about how they describe the "resilience," "strength," and "courage" of these women. Their responses were enthusiastic as we fleshed out how the essence of the English word "resilience" might translate

in the Tanzanian context and in Kiswahili. Three words were referenced: *ujasiri* (courage), *uhodari* (courage), and *uthubutu* (assertive, strong, persevere). Each of these words offers a still deeper meaning and mothers and stakeholders all argued for one or all three of them in their description of mothers who raise their child(ren) with albinism. The most favored word, however, was *ujasiri*. Described initially to me by a female pastor, she said that *ujasiri* means to "Look danger in the eye and say, 'I'll go through it.' " A male pastor later said that it means to "face the lion and fight!" Another definition offered was "the capability to stand by yourself." These powerful descriptions are representative of how I have come to view these women. Faced with impossible circumstances, they chose their children every time. Mothers in this study chose love often in radical opposition to their families, communities, society, and their own comfort. The *ujasiri* that rises up within these women is the element that enables their survival. What furthers their capacity to thrive are what they identified as key supports: Shared experience with other mothers impacted, resources related to safety and security, health, and income. From the data, I see the mothers as deeply courageous and resilient, possessing a perseverance that should not be required from any one individual regardless of geography. Risking idealism and speaking from a position of profound privilege, the capacity built by the mamas' groups where shared experience and support is paramount appears to further this idea of possessing *ujasiri*: As stated a number of times by participants (mothers and key stakeholders alike), "when you empower the woman, you empower the household." There appear to be few "lions" mothers are not willing to face. Chapter Six will further expand on this concept of resilience in the Tanzanian context, including what it means in terms of resourcing women impacted by albinism.

Figure 11. Sharing circle set up beneath a tree.

Summary of Storyline 5: Mothers' Resilience through the Life Stages

From the moment of delivery through to supporting their child's transition into

adulthood, mothers impacted by albinism in Tanzania face several challenges and what I have

termed "(non)choices." Supports that typically fall into place, including the wraparound

postpartum support and care that a woman generally receives from her female in-laws and

neighbours, are suddenly unavailable and replaced by stigma and ostracism. As caretaker,

advocate, breadwinner, and parent, women impacted by albinism are confronted daily with

overwhelming responsibilities in light of human rights concerns, including basic safety and the

right to life of their child. It is concerning that few resources appear to be available for such

women and their families. This research highlighted the vital role that mamas' groups play in the lives of women interviewed as well as income-generating resources supported by *NGO-1* and *NGO-2*. Following the journey from delivery through to discovery of resources illustrates the emergence of resilience.

Chapter Summary

She really wishes that you continue visiting the women and listening to them and listening to their challenges as we all come up with a collective solution to address our challenges. – Goma

The five storylines described throughout this chapter present the complex, intersectional experience of mothers impacted by albinism in Tanzania: from the moment of delivery through to supporting their child(ren) in young adulthood. Women, regardless of where they live in Tanzania, experience the effect of a society that remains unsure how to fully relinquish age-old myths and beliefs around albinism that perpetuate the stereotypes that stigmatize, ostracize, and discriminate against persons with albinism and the mothers that delivered them. Key organizations such as *NGO-1* and *NGO-2* continue to be instrumental in shifting this narrative and creating space for those impacted within their communities. Government resources and NGOs, however, have not consistently sought input or perspectives from mothers of children with albinism. As the experts in their lives and of their families, the voices amplified in this study bring these very experiences to the forefront, imploring society, organizations, and government officials for reflective, responsive action. As is made clear in the findings of this study, mothers know what their families need and are willing to express what is or has been helpful and what is or has not been helpful. As Goma's statement above notes, "a collective solution," one in which mothers are central partners, is fundamental. Time and again I heard

from mothers and key informants: "If you empower the women/the mother, you empower the household." The next chapter will explore, through an Africana Womanism lens, the resilience of these mothers and the manner in which their human rights are and are not enacted within this context.

Figure 12. Waithera and I walking through a village towards an interview location in a mother's home.

Chapter Six: Theorizing the Mothering Experience

This chapter continues to weave the theoretical lenses through which I have encountered and interacted with the narratives and fieldwork, theorizing the lived experience of mothering children with albinism in Tanzania. As presented in Chapter Two (Literature Review), Kromberg et al. (1987) provide the only other research whose primary focus is the experiences of mothers impacted by albinism, and thus the discussion presented here represents a significant new contribution to the evidence base on albinism. Where relevant in this discussion of findings, I will layer in existing albinism research that substantiates my findings, for example, of human rights and SDoH in a general level (i.e., not specific to mothers' experience). Because of this paucity of research evidence, most fruitful in explicating the experiences of mothers are social theories. Specifically, I will explain how I interpreted the data and contextualized the findings using Africana Womanism (Hudson-Weems, 2019), understanding resilience through a social-ecological lens (Ungar, 2013) and vernacularizing human rights (Ibhawoh, 2018). Hudson-Weems' (2019) Africana Womanism, itself rooted in critical perspectives, has been the lens from which I read the data, from fieldwork through to data analysis. Resilience and human rights, starting from the mother's standpoint, are discussed, answering key questions: How might an Africana Womanism lens describe the resilience of mothers impacted? What do human rights mean for these mothers, from their context?

Africana Womanism and Resilience

This section will begin by reminding us how Hudson-Weems (2019) defines Africana Womanism, discussing how I utilized this theory as the lens through which to read the data both in the field and in further analysis stages in Canada. As a woman-centred theoretical framework

rooted in Africana culture versus feminist perspectives largely originating in and adding onto Western feminist perspectives, Africana Womanism provides the cultural context lacking in Western theories. By offering an approach that seeks to honor and value the centrality of family and sisterhood to the female experience in Africana culture, careful not to slide into essentialism where a caricature of the Africana woman is proposed, interpretations of resilience and human rights begin from the standpoint of mothers instead of a Western perspective that would provide an incomplete, obtuse analysis.

Africana Womanism

Africana Womanism, a term coined by Clenora Hudson-Weems in 1987, "identified the ethnicity of the woman being considered, and this reference to her ethnicity, establishing her cultural identity, relates directly to her ancestry and land base – Africa" (Hudson-Weems, 2019, p. 22). Africana Womanism (Hudson-Weems, 2019) provides an Afrocentric lens and framework that requires us to begin from the standpoint of mothers impacted by albinism, acknowledging what their key values and concerns are—which any recommendation or resource must consider. Asante (1987), as the father of Afrocentric theory, asserts that Afrocentricity "means placing African ideals at the centre of any analysis that involves African culture and behavior" (p. 6). While Afrocentric theory could be and, perhaps should be, a chapter all its own, for the limits of this thesis, I acknowledge its place within this analysis as well as acknowledge that in no way is it a suggestion of broad-brush stereotyping, but rather a reclaiming of particular historical, cultural, and traditional values that scholars are arguing are central to any Afrocentric lens (Dove, 1998; Muwati et al., 2011; Pellerin, 2012). As defined in Chapter One, Africana Womanism (Hudson-Weems, 2019) "commands an African-centred perspective of Africana

women's lives—their historical, current, and future interactions with their community, which

includes their male counterparts" (p. 30). Hudson-Weems' (2019) framework emerged during a

period of feminist thought and action largely driven by white American women struggling for

gender equality. While Africana women and other women of colour were certainly part of these

movements, the glaring gaps in the feminist ideology of the time required a response: Race and

class were not central, much less culture. Hudson-Weems (2019), recognizing this gap and

calling it out in the mid to late 1980s, began presenting and publishing her framework, Africana

Womanism, in 1989. Her theory acknowledged that while gender oppression was part of the

Africana woman's experience, the intersection of racism and classism could not be teased out.

This was affirmed by Senegalese philosopher Awa Thiam's (1986) "three-fold oppression" or "3

plagues," sexism, racism, and class division (p. 118). This also landed Hudson-Weems (2019) in,

at the time, the unpopular position of acknowledging the bond in mutual struggle Africana

women had with their male counterparts: race and class oppression. "The Africana

womanist…embraces the concept of a collective struggle for the entire family in its overall

struggle for liberation survival" (p. 29). Indeed, the Africana struggle was much broader than the

white, female struggle, thus requiring a more complex framework. Around the same time,

Crenshaw's (1989) theory of intersectionality was first published. While Hudson-Weems (2019)

acknowledges the benefit of this theory to the overall conversation, her critique exists in the

assertion that intersectionality is an extension of mainstream white feminism that seeks to

"enhance the Eurocentric tool of analysis for Black life," while Africana Womanism is

Afrocentric (p. 107). While not without critique, Hudson-Weems' (2019) framework fits well

within this study as one that begins and ends with the values and particular experiences of Tanzanian mothers in this study.

In response to particularly American stereotypes of the Black woman (e.g., mammies, oversexed, overbearing), Hudson-Weems (2019) outlines eighteen, what she terms, characteristics of Africana Womanism that aim to reclaim, rename, and redefine her: "Self Namer; Self Definer; Family Centred; Genuine in Sisterhood; Strong; In Concert with Male in the Liberation Struggle; Whole; Authentic; Flexible Role Player; Respected; Recognized; Spiritual; Male Compatible; Respectful of Elders; Adaptable; Ambitious; Mothering; Nurturing" (p. 35). I will explore nine of these characteristics in the context of the mothers in this study, demonstrating how these women embody these very characteristics: "Self Namer," "Self Definer," "Strong," "Family Centred," "Genuine in Sisterhood," "Flexible Role Players," "Spiritual," and "Mothering and Nurturing." My interaction with these characteristics and the term itself is a view that they name values and practices that are embedded in social relations, in how an Africana woman might approach life and her story within it.

Hudson-Weems (2019) asserts that, of these 18 characteristics, Self Naming and Self Definer are fundamental. Hudson-Weems (2019) suggests the following:

In African cosmology, it is through the proper naming of a thing that its essence comes into existence—*Nommo*. This powerful first is closely followed by self-definition, a key component in life, which gives top priority status. Our responsibility, then, is to both name ourselves, lest someone else does it, and then proceed to define ourselves and our reality, consciously exercising these elements from our own authentic Africana perspective or worldview. (p. 36)

Particularly in terms of the labelling of persons with albinism (Brocco, 2015), these characteristics are powerful when applied to the experience of persons impacted by albinism in Tanzania. For mothers in this study who have children with albinism, this self-naming and self-defining occurs from the moment they claim their baby with albinism as their own—in protest against the context they find themselves in. While society may call their child *zeru zeru* or *mbuliwmelu* (white goat), they call their child by name and assume the proud title "Mama *Name of Their Child with Albinism*" (e.g., Mama Anna). The strength of these participants to define themselves and their families in the context of albinism, not outside of it, is remarkable and flies in the face of a stereotype suggesting *all* mothers and families abandon their children with albinism. Indeed, the findings of this study stand in direct opposition to this stereotype.

"Strength" is another of Hudson-Weems' (2019) characteristics that mothers in this study clearly embody, suggesting that the strength of the Africana woman is her "realizing and properly accessing herself and her movement, properly names herself and her movement" (p. 37). Mamas attending the *Wamama Wanaojali* groups have lived this out. They are declaring themselves as mothers who care and love. By claiming this name and definition, they are defying the stereotypes rampant in their social context. Even in light of being abandoned and rejected by spouses, in-laws, and communities *because* of the child(ren) they delivered with albinism, these women persist in identifying as mamas. To this point, recognizing the humanity her social context attempts to remove from her, Hudson-Weems (2019) recalls the period of American slavery, where, though White slave owners attempted to remove the Black woman's identity as a mother and companion, the Africana Womanist knew that "despite all, she was a woman and a mother and her white owner had no real control over her personal assessment of her worth nor

her human response to her opinion" (p. 38). Further, as self-definers, Hudson-Weems (2019)

reiterates the collectivism central to an Africana perspective: "[O]ur cultural identity, our

collective presence, supersedes individualism" (p. 39).

This collectivism is further highlighted in Africana Womanism's characteristic of

"family-centrality" (Hudson-Weems, 2019, p. 39). Hudson-Weems (2019) argues that "the

Africana Womanist is more concerned with her entire family, including her male counterpart and

her children, our future generations, rather than with just herself and her sisters. …The survival

of her family is penultimate" (p. 39). This is echoed by Nigerian philosopher on African

ontology, Dr. Elvis Imafidon. Imafidon's (2018) presentation of "patriarchal opportunism" in the

African context anchors much of the argument in the central role that women/mothers play in the

Africana family (p. 173).

> By patriarchal opportunism, I mean the act of taking advantage of, and exploiting, the
>
> inherent quality of, or ability to, care, the maternal tenderness and affection of African
>
> women by African men. Patriarchal opportunism, therefore, begins with the recognition
>
> of African women as the pillar of care and well-being of the African community and then
>
> proceeds for several reasons to the exploitation of this ontological fact about African
>
> women in a manner that is draining, demeaning and abusive to African women. (pp. 173-
>
> 174)

Suggesting that the male ego is "threatened by the obvious strength of care of the African

woman," the man being determined to maintain his position and acknowledgement as "the head"

of the home is part of the reason for this opportunism (p. 174). Within this explanation of

patriarchal opportunism, Imafidon (2018) provides a lens in which to view the frequency at

which men abandon their families when a child with albinism is born—aware that the mother

will parent: "In the African family, the woman cares for all family members" (p. 174). Imafidon

(2018) notes that when men counter the societal norm (e.g., parent their child with albinism in

concert with their female partner), they are chided and teased by their fellow men, indeed by

society. In line with Hudson-Weems' (2019) Africana Womanism's characteristics of "family-

centrality" and "in concert with males in the liberation struggle," Imafidon (2018) calls for

African men to "aim toward mutual care relations with African women" where, among a number

of other practical suggestions, he appeals to men "not taking advantage of the care of women" (p.

175). While fathers remaining with mothers to parent and care for their child with albinism is the

ideal, the current reality facing these women is far from this ideal (Chapter Five). However, as

Hudson-Weems (2019) reminds us, echoed by Dove (1998) in her discussion of mothering,

"family-centrality" extends also to kinship and community. The collectivist nature of the mamas'

groups affirms these characteristics—participants expressed desire to further engage in the

groups and emphasized the value and singularity of the support they receive from them (see

Chapter Five, "Mamas' Groups").

These mamas' groups function as an extension of family and also as a sisterhood, another

key characteristic of Africana Womanism. "Genuine Sisterhood" represents the community of

women, grounded in their shared experiences, social context, and shared "sense of responsibility

for each other by looking out for one another" (p. 43). Mamas' groups offer exactly this kind of

community and sisterhood—one which participants consistently extolled and committed to. This

characteristic provides a lens from which to replay the story outlined in Chapter Five of Inaya

reaching out to Rehema and her child at Ocean Road Hospital. Inaya, a woman integrated into a

mamas' group that has become a supportive social network, recognizes a loneliness and desperation in Rehema, whether as mirrored in her own history or recounted by women in the mamas' groups, and extends a hand of sisterhood by inviting her to join the mamas' group while also giving her the contact information of a key NGO. This is Genuine Sisterhood: no previous relation, simply shared experience, shared humanity, and a communal approach to support.

The characteristic of "Flexible Role Players" is key to understanding the experiences of mothers in this study. Hudson-Weems (2019) positions the concept of Flexible Role Players within the history of American slavery—identifying the ways in which slavery removed traditional roles from men and women. Within the current Tanzanian context, however, aspects of this concept resonate, particularly in terms of mothers impacted by albinism. Mothers in this study explained how, following the birth of their child(ren) with albinism, they were forced to assume other roles due to the impact of partners leaving or refusing paternity and in-laws and the broader community rejecting them. Typically, following the delivery of their child, female relatives and women in their community would assist the new mother with managing her home and minding her other children. However, with the birth of a child with albinism, not only did the mothers in this study describe the loss of this "village" of support, they also described having to manage finances and determine how to shelter and feed their families with minimal to no support. Hudson-Weems (2019) notes that from the Africana perspective/tradition, "men are still considered protectors in most circles, thereby expected to uphold the family and defend both their women and children on any and all levels if need be" (pp. 42-43). This stands in direct contrast to the experience of mothers in this study who must gather their strength and capacity and become sole bread winners for their families while managing the household and attempting

to ensure shelter, nutrition, and education are provided. As many of the fathers described in this study evaded their responsibilities, mothers had to assume new roles.

"Spirituality" is the characteristic that underpins the others (Hudson-Weems, 2019). As identified in Chapter Five, belief in the supernatural and a Divine Being (i.e., God) was communicated as the foundation of what gave the mothers interviewed purpose, identity, acceptance, and hope. Whether it was in describing how they accepted their baby with albinism as "a gift from God," also experiencing this as a sense of broader purpose, or in attributing opportunities or help as God's provision, mothers in this study identified with their faith and the supernatural (Chapter Five). It is interesting to consider how myth and belief in the supernatural are also embedded within negative views and violence against persons with albinism. Mothers and key informants were clear in their distinction of God versus the supernatural powers attributed to witchdoctors and their witchcraft. Hudson-Weems' (2019) statement that "in African cosmology, the physical and spiritual world coexist and, hence, both realities complement each other in working for the good of all in the universe according to God's will," certainly rings true in the context of mothers in this study—dependent upon the supernatural to intervene (p. 46). Both characteristics of strength and spirituality connect with the next section on resilience, exploring the movement from strength and survival to resilience.

Finally, the characteristics of "Mothering and Nurturing" were palpable in the stories shared by mothers in this study. Hudson-Weems (2019) declares that:

> [T]he Africana womanist is committed to the art of mothering and nurturing, her own
>
> children in particular and humankind in general. This collective role is supreme in
>
> Africana culture, for the Africana woman comes from a legacy of fulfilling the role of

supreme Mother Nature—nurturer, provider and protector. …She must remain consistent in doing what must be done for the survival of the entire family, a commitment solidly grounded in and realized through a positive sense of history, family-hood and security, all of which true mothering and nurturing provide. (pp. 48 – 49)

Outlined in Chapter Five were the expressions of enduring love for their children with albinism and the painful decisions they face(d) in terms of bringing their children to government holding centres for safety or seeing their children sponsored in NGO programs to attend boarding school. Important to note is how this separation is the antithesis of mothering from their perspective. There was nothing about separation that made sense for these women beyond protecting life and limb and the opportunity for their children to receive an education that would pave a *safe* and *different* path for their future (i.e., break the cycle of poverty). The term I have used for these decisions has been (non)choices. While mothers express pain in separation and the difficulty of arriving at this decision, there appeared to be little doubt that, within the current environment in Tanzania, it is necessary. And yet, mothers voiced concern in asking those in charge at the boarding schools and at *NGO-1* to grant them uninhibited access to their children and to parenting: increase agency and choice. Mothers are central to successes of any kind and when we champion women, we champion children and family. Research has shown that women, by and large, will choose the well-being of their children before most other things (van der Mark, Conradie, Dedding, & Broerse, 2019). Hudson-Weems' (2019) assertion of Mothering and Nurturing as characteristics of the Africana woman aligns well within this understanding and is affirmed by other Africana scholars (Dove, 1998; Muwati et al., 2011; Pellerin, 2012).

Hudson-Weems' (2019) framework of Africana Womanism, anchored by the eighteen characteristics of the Africana woman, highlighted for me as an outsider and researcher how women such as the mothers interviewed in this study are experiencing their everyday within a broader narrative of Africana history and culture. Africana Womanism helps us to "see" the practices that are important to the experience of mothering in the Tanzanian context, helping us to contextualize the storylines in Chapter Five. In Hudson-Weems' expansion on Self Namer, Self Definer, Strong, Family Centred, Genuine in Sisterhood, Flexible Role Players, Spiritual, and Mothering and Nurturing, I was able to track the storylines I heard mothers express over and over throughout fieldwork and in analyzing the data. These mothers resist discrimination, stigmatization, ostracism, and human rights violations perpetrated on them and their children because of colourism and cultural/spiritual myths and beliefs about albinism. This framework reinforces the collective experience and the collective support that mothers interviewed expressed and called for. Further, this framework embodies the Kiswahili terms, presented in Chapter Five, that I was told reflected the concept of resilience: *ujasiri*, *uthubutu*, and *uhodari*. Particularly *ujasiri*, in which a female pastor described as "to look danger in the eye and say, 'I'll go through it.' " This kind of resolve and strength is powerful, and yet, lest we slide into labeling the "Strong African Woman," the fact is these mothers should not have to display this level of strength to ensure they and their families survive infringement of their human rights. Therefore, we cannot leave it here. There must be accountability on the environment and structures in which these mothers live their daily lives.

The relevance of Africana Womanism for the research at hand on mothers of children with albinism in Tanzania is affirmed by the work of various Africana scholars exploring

motherhood (Dove, 1998; Muwati et al., 2011; Pellerin, 2012). However, as a theory it is not without important critique (Alexander-Floyd & Simien, 2006). Hudson-Weems' (2019) Africana Womanism has been hailed by proponents as the Afrocentric theoretical framework to address race, class, and gender oppression that various brands of feminism have tried to achieve within a Eurocentric paradigm (Dove, 1998). However, scholars critical of the framework suggest that Hudson-Weems' work excludes the work of Black feminists and risks promoting an essentialized Africana woman (Alexander-Floyd & Simien, 2006).

Pellerin (2012), in her study seeking to "actively engage Africana women as agents of their own image liberation" using a photo-biographic method, asserts that research with Africana women "must include recognition of the centrality of motherhood" (p. 77). Indeed, her study participants affirmed key components of Africana Womanism including the centrality of motherhood, family, and community in the photos they chose to describe and depict their identities as Africana women (Pellerin, 2012). Dove (1998), based on her research with Africana mothers, acknowledged that theories attempting to address the African woman's experience "have largely been inadequate. Those related to the feminist tradition, both White and Black, have critiqued the social conditions of women within Europeanized societies and sought solutions within European paradigms" (p. 515). Indeed, Dove (1998) furthers Hudson-Weems' framework by deepening the links to culture.

Conversely, Alexander-Floyd and Simien (2006) argue that "the master narrative and characteristics upon which [Africana Womanism] is based ignore and distort Black feminist thought and history, fail to join theory with practice, and depend on an ahistoric, monolithic view of African cultures" (p. 68). Critical of Hudson-Weems' (2019) ranking of race, class, and

gender (in this order), Alexander-Floyd and Simien (2006) align with other Black feminist

scholars (citing Kimberly Crenshaw, Patricia Hill Collins, and bell hooks) in their argument that

these identities cannot be separated or made distinct—the complexities are interacting at once. In

critique of Hudson-Weems' eighteen characteristics defining a "true" Africana woman,

Alexander-Floyd and Simien (2006) state that they "represent a litmus test for identifying those

women who are or who are not sufficiently Black or Afrocentric. Those who remain loyal to the

race affirm, adopt, and/or exhibit the attributes of the Africana womanist" (p. 78).

   While acknowledging the risk of essentializing the Africana Woman or suggesting the

experience of mothers in this study as homogenous, I have tempered the use of this framework

by making myself aware of these critiques. However, given its focus on culture and assuming an

Afrocentric stance, my belief is that it indeed remains a helpful framework from which to deepen

the analysis of this focused critical ethnography, despite and in recognition of its critiques. The

following section introduces a nuanced understanding of resilience that moves far beyond the

Eurocentric, Western definitions that highlight individual attributes as responsible for someone

either being or not being resilient. Rather, I explore how a more fulsome understanding of

resilience accounts for these mothers' best efforts in the face of human rights infringements and

violations that prevent them and their families from thriving without a fully engaged social

ecology (Ungar, 2013).

Resilience

   Ujasiri. Uhodari. Uthubutu. In the context of mothering children with albinism in

Tanzania, what does resilience look like and how does it differ from survival, with which they

are well acquainted? Resilience, also described as "resistance to the effects of exposure," is

absolutely demonstrated by the mothers in this study (Ungar, 2013, p. 255). However, how might resilience actually enable well-being and family flourishing? While not applying Africana Womanism to his theory of social ecological resilience per se, the many shared inferences within Ungar's (2013) theory help us consider the resilience of these mothers through an Africana Womanism lens. Ungar's (2008, 2012, 2013; Libório & Ungar, 2014) theory of resilience, affirmed by South African colleagues (Theron, Theron, & Malindi, 2013), would suggest that a mother's resilience is either fostered towards flourishing and well-being or diminished as a direct result of the social ecological environment in which they live. This shift away from viewing resilience as purely individual, the Eurocentric perspective, is currently being explored in other contexts such as amongst Indigenous Canadian communities—acknowledging the role of history, colonialism, and culture (Kirmayer, Dandeneau, Marshall, Phillips, & Williamson, 2011). Kirmayer et al. (2011), echoing Ungar (2008), suggest that the study of resilience should be undertaken "in collective and cultural terms to identify social-structural barriers to the expression of resilience at crucial life transitions" (p. 85). A social ecological definition of resilience, therefore, holds a mother's community and government accountable for capacity building rather than mothers bearing the sole responsibility. This is further detailed by Ungar's (2013) following statement:

> This social ecological understanding of resilience implicates those who control the resources that facilitate psychological well-being in the proximal processes (e.g., making education accessible; promoting a sense of belonging in one's community; facilitating attachment to a caregiver; affirmation of self-worth) associated with positive development in contexts of adversity. (p. 255)

When resources are in place at the local and national level, such as health and social services,

security, infrastructure, mamas' groups, access to food, shelter, education, and employment, this

study demonstrates capacity is built in a cumulative manner. That is, mothers could be further

empowered to move from survival and a disadvantaged resilience towards a resilience that

fosters well-being because, as they reach out for assistance, *something* would be extending a

hand in return (i.e., resources, responsive systems in place).

This study builds on existing work that has touched on the resilience of women and

families impacted by albinism (Butler-Jones, 2013; Lynch et al., 2014). Using two instruments to

measure trauma and resilience, Butler-Jones (2013) identified "themes of high traumatic

experience and high resilience" (p. 109). Such resilience included faith (or religious belief),

which Lynch et al. (2014) also identified as a protective factor influencing families' resiliency in

the face of adversity, discrimination, and stigma. In recommending further research related to the

resiliency of women impacted by albinism, Butler-Jones (2013) identified women in her study,

as in this study, as being an untapped resource in terms of albinism education to communities

and professionals alike. This study undertaken with mothers identified the silence of their voices

in literature and resources—recognizing that participants are a storehouse of knowledge,

experience, and passion that could not only assist government, policymakers, NGOs/CSOs in

their efforts, but would also have an empowering benefit on the mothers themselves. Speaking to

the silenced experiences, Ungar (2012), notes "across contexts and cultures, the voices of

disadvantaged people are not privileged…which means they go largely unheard when it comes to

designing services that matter most to resilience" (p. 388). Adding the narratives in this study to

the literature, including by way of submitting memos to partnering NGOs that summarize the

data collection, findings, and recommendations, brings the voices of mothers and their families

impacted to the table. No longer can we say, "We just don't know what they need."

In connecting Ungar's (2013) social ecological resilience, Hudson-Weems' (2019)

Africana Womanism, and the voices of mothers in this study, we begin to see markers for where

broader systems and structures are needed to engage. Ungar (2013) describes "seen protective

factors" (p. 259), which align with many of Hudson-Weems' (2019) Africana Womanism

characteristics described above, that enable the environment women live and mother in to be

considered. Protective factors include "supportive relationships, opportunities to experience a

powerful self-definition, experiences of efficacy, experiences of social justice, access to material

resources like food, education and housing, a sense of cohesion within one's family, community

or school, and cultural adherence" (Ungar, 2013, p. 259). The Africana Womanism

characteristics of Family-centrality, Genuine in Sisterhood, Strength, Self-Definer, and Self-

Namer are particularly represented within Ungar's (2013) discussion of protective factors that

"account for positive adaptation" towards resilience (p. 259). These characteristics, together with

aforementioned protective factors, foster an environment in which resilience that effectuates

well-being and flourishing can exist. To this point, Ungar (2013) asserts that for individuals such

as the women and families in this study "who are coping with highly adverse family and

community contexts, individually focused interventions are less likely to foster well-being than

interventions that first mitigate exposure to risk factors like violence, poverty, and social

marginalization resulting from immigration, homophobia, and racism" (p. 263). While the lens of

Africana Womanism (Hudson-Weems, 2019) stresses that we recognize mothers in this study as

embodying Africana characteristics as listed above, Ungar (2013) and Kirmayer et al. (2011)

challenge researchers, government, policy makers (i.e., those in positions of power, privilege, and authority) to address system level and structural risk factors that mothers in this study mentioned time and again. These factors include: poverty, marginalization, colourism related to albinism, health inequities, lack of education and employment. Such inadequacies at the system level hold these women and their children back from experiencing the fruit of a resilience that further enables a holistic health and well-being. The following figure (Figure 13) illustrates the realization of social ecological resilience within the context of mothers impacted by albinism in this study. Well-being and flourishing are enabled when, despite ongoing risk factors, a mother's capacity to cope and survive, bolstered by protective factors such as those found in Africana Womanism, is met with capacity from her social ecology.

Risk Factors
(SDoH, Stigma, Discrimination, Threats to Human Rights)

Protective Factors:
Mothering/Nurturing
Flexible Role-Player
Self-Namer/Definer
Family-Centred
Sisterhood
Spiritual
Strength

Well-being & Flourishing

Environmental Factors (i.e., social ecology):
Access to Effective/
Meaningful Resources
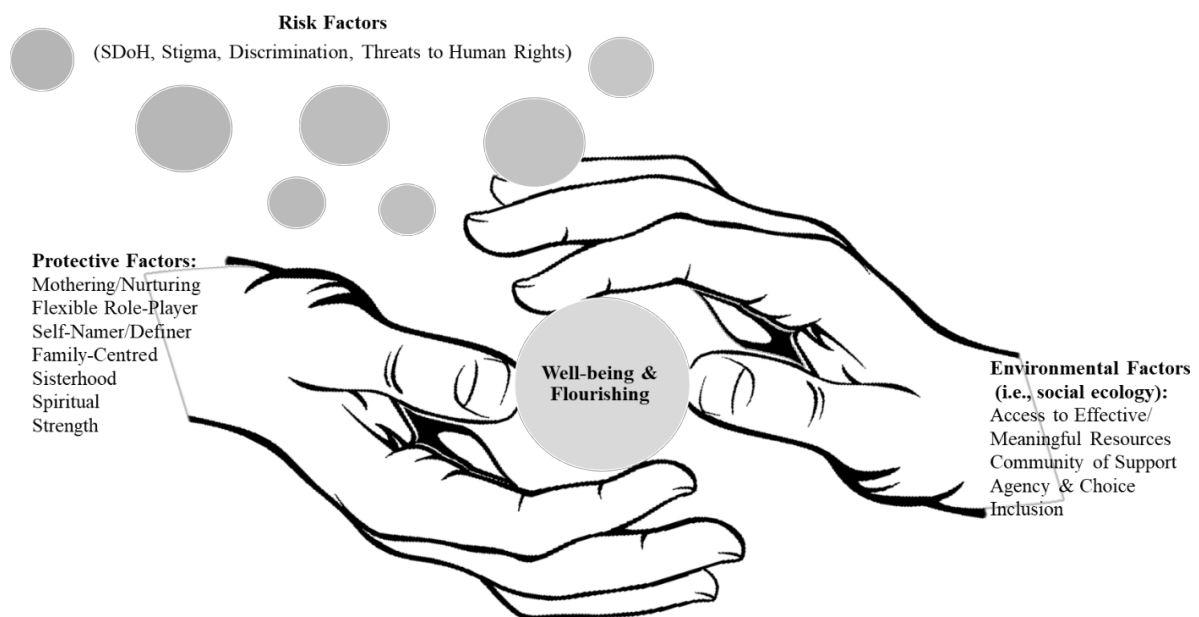Community of Support
Agency & Choice
Inclusion

Figure 13. Social ecological resilience in the context of mothers impacted by albinism.

The characteristics in Africana Womanism are to be empowering, as are the mamas' groups and the support for them provided by both NGOs highlighted in this study. When such resources and supports empower these characteristics they can be protective factors. However, when resources or supports are not in alignment with these characteristics and the values voiced by mothers themselves, they can become prohibitive or even risk factors to well-being and family flourishing (e.g., separation from their children, especially where barriers to parenting exist). Indeed, Ungar (2008) warns that "we must understand the context in which the resources to nurture resilience are found in order to avoid hegemony in how we characterize successful development and good coping strategies" (p. 221). Particularly, when foreign NGOs are determining programs and resources, avoiding Eurocentric approaches are required to avoid this hegemony.

In considering this risk of missing alternate coping strategies within adverse contexts outside of Eurocentric frameworks, Ungar (2013) argues that we must actively acknowledge and look for them. This study provides several examples that illustrate such resilience from the practical level to the psychosocial, for example, navigating various "opportunities" to generate income from selling fruit at a roadside stand to learning a new craft for selling as part of a mamas' group collective. Another key example that gets to the heart of mothering in the context of albinism in Tanzania is how mothers navigate separation from their children in the context of government holding centres and boarding schools. The care and strength required in bringing their child to holding centres for protection and education, responding to an environment failing them and their children (i.e., unable to ensure safety in their own communities, ongoing discrimination), is for many beyond comprehension. However, for the mothers whose stories are

represented in this study, their resolve in the face of such (non)choices to continue to reach out and connect with other women living out shared experiences, remaining open to options for support and income generation, certainly demonstrates "resistance to the effects of exposure, also termed resilience" (as defined earlier in this section) (p. 255). This example, highlighting the diminishing effects of the absence of coordinated, effective, and meaningful structural responses, does illustrate an individual resilience where a woman's social ecology is not conducive to building on her resilience in such a way that promotes and sustains well-being. Mothers in this study indeed demonstrate this level of resilience. However, they are appealing for resources that would engage their current efforts. This desire to engage with their social ecology is waged in the balance of a country facing various demands on its developmental and infrastructure priorities. However, what these women request are often services already available for those families Imafidon (2020) identifies as the melanin-privileged, such as non-discriminatory education, access to health care equipped to educate patients on their condition, or access to medications required (sunscreen has not yet been classified as a prescription medication for persons with albinism).

As referenced, Eurocentric definitions of resilience look to an individual person's ability to "bounce back" following a traumatic experience. This definition was used by Butler-Jones (2013) in exploring the help-seeking behaviours and resilience of women with albinism in Tanzania. While her dissertation was an important start to the conversation, Ungar's (2013) social ecological conceptualization of resilience provides both the contextual and cultural components necessary to evaluate this concept from an Afrocentric perspective—moving the analysis forward. "The ecological definition purposely decentres individuals to avoid blaming

them for not flourishing when there are few opportunities to access resources" (p. 256). This

dissonance between Western conceptions and Ungar's definition is something of a "resilience

fallacy." Ungar (2013) asserts that "an overemphasis on personal agency and other aspects of

what has come to be known as 'resiliency' naively assumes that individuals survive only because

of a positive attitude or other fiction" (p. 256). These "other fictions" include things like seeking

help and resources where the proper resources and help do not exist or are not responsive.

Ungar's (2013) framework of resilience requires us to consider the responsibility of inadequate

or hostile environments. From a Eurocentric viewpoint, help and resources are typically a phone

call or referral away. For the mothers in this study, such resources are hardly existent, save for

the mamas' groups. With the exception of this resource, no other woman/mother-centred

resource was identified by participants within this context. Mamas' groups appear to provide the

ecology that Ungar (2013) argues enables resilience: "I defined resilience as the capacity of both

individuals and their environments to interact in ways that optimize developmental processes"

(p. 256). These mamas' groups also provide some of the protective factors that promote

resilience, such as community cohesion, access to a support network, opportunity to earn an

income and build skills for future employment, and the fostering of self-worth and self-esteem.

Most importantly, most mothers in this study lauded these mamas' groups as the *only* source of

psychosocial and economic support, reinforcing the following statement by Ungar (2013):

> Therefore, a social ecological interpretation of resilience emphasizes cultural sensitivity:
>
> A resource is only useful if it is valued. Individual resilience occurs when there is an
>
> opportunity structure (an environment that facilitates access to resources) and a

willingness by those who control resources to provide what individuals need in ways that

are congruent with their culture. (p. 256)

This study demonstrates that the mamas' groups and the NGOs supporting them are currently the

single "opportunity structure" supporting these women in meaningful ways as identified *by them*.

While not perfect, with mothers requesting *more* agency and choice in terms of their groups and

how NGOs interact with them as parents and caregivers, these were the singular resources voiced

by mothers in this study as responding to their particular need.

As articulated in Hudson-Weems' (2019) Africana Womanism framework, the centrality

of sisterhood, kinship and community in the Tanzanian way of life is paramount. Ungar's (2013)

acknowledgement that the way in which a Eurocentric understanding of resilience is

"incongruent with the more relational worldviews of communities" such as those communities in

which mothers in this study find themselves, highlights how their situation is made that much

more painful. When mothers are forced outside of this communal fabric of support and kinship,

they lose their army. The army of support and defenders that is responsive to those in the

community that ascribe and fit the norm—those that are not other. This concept is rooted in the

South African term *Ubuntu*: I am, because you are. This idea will be explored in the following

section on human rights. However, here it helps focus our perspective on how mothers impacted

by albinism are experiencing an ostracism and isolation from what was largely portrayed to me

as the typical Tanzanian approach to family and neighbor. Therefore, even more, Ungar's (2013)

theory of resilience supports the call for mothers' social ecologies to engage and participate in

meaningful ways identified by mothers themselves: "The personal agency of individuals to

navigate and negotiate for what they need is dependent upon the capacity and willingness of peoples' social ecologies to meet those needs" (p. 256).

Mechanisms to Foster Resilience

This following section considers how Ungar's (2013) social ecological resilience could be fostered within the Tanzanian context to enact and ensure human rights of mothers and their children impacted by albinism. Anchored in global health perspectives, the UN Sustainable Development Goals (SDGs) (UN, 2015) help us consider how fostering the human rights of mothers can begin by utilizing the framework already espoused in the SDGs, specifically, SDG #3 (good health and well-being) and #5 (gender equality). Using Ibhawoh's (2018) work on human rights in Africa, particularly the concept of vernacularizing human rights to the local level, I will explore how the environment might foster the resources required for mothers' resilience to be fully realized. When Ungar's (2013) protective factors are employed, building upon the Africana Womanism characteristics that mothers in this study already possess, vernacularizing human rights is the next layer that works to ensure mothers and their families attain well-being and have access to flourishing within their society. This conceptualization of human rights is the natural foundation embodied in *Ubuntu*: I am because you are.

Human Rights

The findings chapters (Chapters Four and Five) give insight into how human rights were experienced by mothers impacted by albinism. Specifically, the following articles that Tanzania has adopted under UN conventions are all evident in the mother's narratives. Despite this human rights protection, mothers were separated from their children due to risks to their safety and security. Following from the details presented in Chapters Four and Five, there is evidence in

this study to support that all of the following human rights, as outlined by the UN Committee on

Economic, Social, and Cultural Rights (CESCR) (1993) and the African Charter on the Rights

and Welfare of the Child (Organization of African Unity (OAU), 1990), of mothers impacted by

albinism are violated: Right to Adequate Standard of Living; Right to Health; Right to Social

Security; Right to Protection and Assistance for the Family; Right to Education; Right to

Protection of the Family; Right to Parental Care and Protection; Right to Parental

Responsibilities; Right to Protection against Harmful Social and Cultural Practices; Protection

from Sale, Trafficking (including body parts, organs, hair, fingers, nails, blood, bones), and

Abduction; Right to Non-Discrimination; Right to Work; and the Right to Access to Justice

(UNGA, 2019b). This exhaustive list could read as signposts for government and local and

international stakeholders to consider where their impact could most readily be engaged. The

details of Imara's story in Chapter Four help us to consider the human impact of several of these

human rights violations. For Imara, these include exactly some of these violations mentioned

above, including the right to parental care and protection (Articles 19 and 25 of the African

Charter on the Rights and Welfare of the Child [OAU, 1990]); protection and assistance for the

family (African Charter - Article 18 [OAU, 1990]), and CESCR Article – 10 (UN CESCR,

1993); the right to work (CESCR - Article 6) and the right to social security (CESCR - Article

9). Perhaps, then, one of the main findings of this study is the multiplicity of human rights

violations that mothers navigate on their road to resilience.

    Given the very present concern of securing the human rights of women and their families

impacted by albinism, linking this study to the framework laid out within the SDGs is critical.

Ero, in her work as Independent Expert on the enjoyment of human rights by persons with

albinism, has anchored much of her mandate on the UN's commitment to start with "the furthest

behind first" (UN, 2015, p. 7). As a marginalized, minority community experiencing systemic

and structural discrimination, stigmatization, and ostracism, largely silenced in current policy,

mothers and children in this study are indeed amongst the "furthest behind." The SDGs provide

an accountability tool for broader government and policymakers within Tanzania, offering a way

to measure, assess, and advance human rights particularly for persons impacted by albinism,

along with their families. Two of the SDGs provide an excellent grounding for work particular to

the gendered nature and experience of albinism: good health and well-being (Goal 3) and gender

equality (Goal 5). Both of these goals, when considered from the purview of both UN Women

(Browne, 2017) and the UN Convention on the Rights of Persons with Disabilities (CRPD) (UN

Department of Economic and Social Affairs, 2018), anchor the particular experience of mothers

impacted by albinism. Government and policymakers should ground their next steps within these

frameworks. Further, they should be centred on dialogue with mothers impacted by albinism

themselves. As a largely untapped source of knowledge and expertise in their own lives and the

situations of their children, their voices should be involved in all policies that impact their lives,

livelihoods, and well-being, moving towards gender equality and equitable access to health care.

As outlined in Chapter Two (Literature Review), little research in the field speaks

explicitly to human rights (Burke et al., 2014; Franklin et al., 2018; Masanja & Magembe, 2015;

Reimer-Kirkham et al., 2019) and not a single article features discussion around human rights

and the experience of mothers specifically. This study addresses this lack in current research

literature in such a way that invites deeper analysis and opportunity for further research. In her

reports, Ero, UN Independent Expert, has explicitly highlighted the particular vulnerability of

women and children impacted by albinism (UNGA, 2016b, 2017b, 2018, 2019a). Most recently,

published in December 2019, Ero's report to the 43rd session of the Human Rights Council

(UNGA, 2019a) focuses solely on women and children impacted by albinism, with particular

references to mothers of children with albinism. This is a remarkable step towards promoting and

ensuring the human rights of mothers impacted, providing a much-needed framework for a

multisectoral response. In recent years, discussion around ensuring the human rights of children

with albinism (Franklin et al., 2018) has begun to lay the groundwork for considering human

rights from a family-centred perspective, as children are inextricably representative of family and

community. Indeed, Burke et al. (2014), in their findings, discussed that, in Tanzania, "human

rights are situated within a legal framework in which the state is that agency that guarantees

human rights, but it also positions rights as the responsibility of the community," including both

perpetrators and protectors (p. 128). This study further suggests that any conceptualization of

human rights within the Tanzanian context must not only engage the broader community but also

be community-centred.

 Archbishop Desmond Tutu, as the head of the Truth and Reconciliation Commission in

post-apartheid South Africa, provides an explanation of the South African word *Ubuntu* as the

concept that "encapsulates the notion of an interdependent humanity that is central to indigenous

African cosmology" (Ibhawoh, 2018, p. 31). Ibhawoh (2018) offers the following interpretation

of how Ubuntu is enacted:

 "My humanity is caught up in your humanity, and when your humanity is enhanced—

 whether I like it or not—my humanity is enhanced. Likewise, when you are

 dehumanized, inexorably, I am dehumanized as well." It is a distinctly African take on

the golden rule or law of reciprocity, which is evident in many religions and cultures. (p.

31-32)

Adopting a Tanzanian interpretation of this, Julius Nyerere, Tanzania's first Prime Minister and

then President following liberation from colonial rule in 1961, argued an embodiment of

Ujamaa, the Kiswahili interpretation of *Ubuntu*, suggesting togetherness, unity, and equality.

Ujamaa was used to promote Nyerere's championing of his philosophy of socialism in

Tanzania's early years as a country (Ibhawoh, 2018).

In personal communications with stakeholders, during my time in Tanzania and since

returning, *Ubuntu* appears to be wrapped up in the concept of *Ujamaa*. In a followup email

exchange between stakeholders and myself, the concepts of *Ubuntu* and *Ujamaa* were at once

combined and similarly defined to eventually be suggested as going in somewhat different

directions. As political as *Ubuntu* would have been when taken up by Archbishop Tutu, so too

Ujamaa has a strong political force as it came to be during Nyerere's leadership in Tanzania.

Ubuntu remains a communal and human to human philosophy. That said, a key stakeholder (A.

Gwacha, personal communication, January 12, 2020) reflected how in Tanzania "we believe in

community that surrounds us and that every child belongs to everyone in that community…it is

the job of everyone to take care of [your] fellow man." She went on to explain the concept of

Ujamaa as rooted in this concept of community extending to the sharing of resources to ensure

the community as a whole is taken care of. The latter clearly introduces Nyerere's promotion of a

more political socialism that naturally fit into what Ibhawoh (2018) describes as very much a

part of an "African cosmology" (p. 31), and what Imafidon (2017) refers to as an African

ontology. If the work of promoting and ensuring the human rights of persons with albinism

begins within these cultural conceptualizations of community-centred care and living, interrupting myths and beliefs will perhaps be more plausible.

Indeed, there is an entire Christian theology devoted to *Ubuntu* (Membe-Matale, 2015). Membe-Matale (2015) argues that the "transformative spirit that connects us to others" in *Ubuntu*, "inspire[s] us to stand firmly against marginalization and discrimination" (p. 274). She goes on to connect the deep underpinnings of human rights to this theology of *Ubuntu:* "It seeks the redemption of the whole earth, resists life-destroying values, and inspires us to discover innovative alternatives that promote life in all its forms" (p. 274). Within the Tanzanian context, linking *Ubuntu* to African ontology and Christian theology carries important implications for a way forward to ensuring the human rights of mothers impacted by albinism. This will be further discussed in the next chapter on recommendations.

Because human rights discourse can seem inaccessible at the highly global level (i.e., at the level of the United Nations, the African Union), Ibhawoh (2018) offered the approach of a "vernacularized universal human rights" in which "universal human rights have intrinsically local dimensions since they gain meaning when applied to local contexts" (p. 226). *Ubuntu* and *Ujamaa* begin this vernacularization of human rights at the local level and *Ubuntu* theology captures even more complexities. Further, a vernacularized human rights acknowledges human rights as embedded within broader narratives—embedded in the everyday cultural, religious, spiritual, and political practices of societies. Ibhawoh (2018) notes that "African-ists who must work often with oral histories are familiar with the benefits of multiple tellings of a story. When a story is told from several perspectives, each retelling helps the listener appreciate its inherent

complexities" (p. 25). The narratives of mothers impacted by albinism, recounted in this study,

give witness to complexities of human rights violations experienced in the everyday.

Integrating the Analytic Contributions of the Study

Interpreting human rights alongside Ungar's (2013) social ecological resilience, and

drawing on the characteristics provided by Hudson-Weems' (2019) Africana Womanism allowed

for, at the least, an appreciation of the cross-cutting, multisectoral and intersectional implications

for mothers of children with albinism. Yet, much of their experience exists outside of the

idealized Africana way of life that Hudson-Weems (2019) inadvertently reifies. There is a draw

to perpetuate an essentialized narrative of the "Strong African Woman" who survives despite

multiple and intersecting forms of vulnerability related to various SDoH. While not denigrating

the capacity of mothers of children with albinism, we must acknowledge that they are

experiencing various (non)choices that accompany their structural vulnerability. Their ability to

climb out of poverty, further their educations, obtain gainful employment, and experience the

support of family and community are all hampered by the fact that the child(ren) they have

delivered have what is an unacceptable and misunderstood condition within their broader

society. Their choice to rise to the occasion, arguably, has nothing to do with choice. All 17

mothers in my study expressed unconditional love for their children with albinism—they

sacrificed their own choices to raise their child(ren). Of course, these women are strong: This is

obvious, but my caution is that this emphasis on their strength can result in policymakers and

leadership overlooking the social ecological conditions and structural/system level inadequacies

that require them to be so strong. Their ability to be strong should be removed from the equation

when considering policies and system level responses that would improve the situation of

mothers and their children affected by albinism. This argument requires much more deliberate

dialogue to appreciate the underlying determination that these mothers demonstrated for their

children.

Resources impact a mothers' ability to begin taking back choice. Perhaps it is the

resource of fellow women who too can relate, like *Wamama Wanaojali*, or health services that

mean she does not have to worry about regular vision care, skin care, and sunscreen. Perhaps it

means policies that ensure fathers who choose to leave their children are accountable, at least

economically, to support mother and child. Perhaps it is envisioning a community that

understands what albinism actually is and chooses to disregard myths and superstitions that have

hurt women and their children impacted by albinism for generations.

Indeed, these mothers are strong and they are resilient in the face of impossibly difficult

circumstances, but they should not have to be as strong and resilient as they are. Their societies,

communities, and governments have ultimately denied them the rights that should be bestowed

to all people. Their social ecologies are not conducive to coming close to well-being and human

flourishing. These women are busy advocating for the daily needs of their children: shelter, food,

schooling, health care, eye care, safety and security. Yes, these mothers are strong and resilient,

but we cannot lose the central point: They should not have to face what they do as a result of

albinism.

Chapter Summary

In this chapter I have described how I employed the lens of Africana Womanism

(Hudson-Weems, 2019) to deepen the analysis of the findings using social ecological resilience

(Ungar, 2013) and a vernacularized human rights framework. These perspectives grounded the

analysis within the Tanzanian context, being mindful and intentional about avoiding application

of Eurocentric, Western frameworks to the concerns voiced by the women and stakeholders in

this study. The UN SDGs, specifically goals 3 and 5, were applied for illuminating access to

equitable health care and gender equality as interrelated when addressing the human rights of

mothers and their children impacted by albinism. Overall, Hudson-Weems' (2019) Africana

Womanism's deeply embodied characteristics of Self Namer, Self Definer, Strong, Family

Centred, Genuine in Sisterhood, Flexible Role Players, Spiritual, and Mothering and Nurturing

contextualized the lived experience of mothers impacted by albinism and engaged with Ungar's

(2013) definition of social ecological resilience that accounted for the environments that mothers

and their children with albinism are confronted with. These environments, severely lacking in

support and resources, demonstrate the various violations to the human rights of mothers and

their children. Vernacularizing human rights, or applying them to the local level, draws on

concepts of *Ubuntu* and *Ujamaa* which are, inherently, deeply community-centred, calling on a

human rights response that accounts for all humans recognizing the humanity in the other. In the

next chapter, I will offer a summary of findings, conclusions of this study, and recommendations

at the policy, health and social services, civil society, education, leadership, and research levels.

Figure 14. Taking a break from a Sharing Circle. Water, cookies, the interview guide, and my notebook foreground a mother walking outside with her young child with albinism.

Chapter Seven: Summary and Recommendations

The purpose of this study was to explore the social influences on the experience of mothering children with albinism in Tanzania. In this final chapter, I will present a summary of the findings and outline key conclusions. As a final point, I will propose recommendations for policy, civil society, health and social services, education, research, and leadership in terms of partnering with mothers impacted by albinism.

Summary of the Findings

Using the method of focused critical ethnography over 10 weeks of fieldwork, separated into two trips, in the Dar es Salaam and Mwanza regions of Tanzania, this study explored the social influences that shape the lived experience of mothers of children with albinism in this context. Using semi-structured interviewing, I interviewed participants individually and/or in sharing circles alongside Waithera (cultural liaison) and other interpreters. This study's sample is part of a broader study which involves sharing circles and interviews (*N*= 62). For the primary sample of this study, I drew on the narratives of six mothers. Another 12 mothers' experiences, suggestions, or reflections are included in a secondary sample. To further understand the context and services or resources available, I also drew on interviews with six key stakeholders. Thus, the total sample for this thesis was 24 participants (*N*=24).

Using the lens of Hudson-Weems' (2019) Africana Womanism, several key storylines were derived from the case study of Imara (Chapter Four). These storylines were expanded on by drawing on the parallel and counter narratives from other participants (Chapter Five): *Social Context: Situating Mother's Experiences*; *Safety and Security: Carrying the Burden*; *Role of NGOs: Resourcing a Gap*; *Sponsorship and Mothering: Responding to Separation*; and

Mothering: Resilience through the Life Stages of Parenting. Within each of these broader storylines, several subplots were discerned that further illustrate how women navigate the burden of parenting largely on their own. Each storyline bears the effects of partners/spouses leaving once a child with albinism is born, in-laws refusing kinship, and their communities ostracizing and stigmatizing them and their children. Mothers' experiences are described against the backdrop of the broader context of little access to life-sustaining, life-enabling resources such as health and social services, employment, affordable education for their children, and the continued threats of attacks and abductions of their children. Vulnerable to an array of situations that their social ecology does not protect them from, mothers survive their situation based on strength and resolve to mother their children. In Chapter Six, Ungar's (2013) concept of social ecological resilience was applied to mothers' context as I argued that, despite mother's strength and resolve, their environments largely fail to enable their well-being and family flourishing.

This study confirmed that mothers' primary concerns are ensuring safety and security for their children with albinism, and ensuring they have shelter, food, and lifesaving sunscreen (Objective 1). Mothers articulated that *NGO-1* and *NGO-2* provide the main source of health and social services in the forms of mobile clinics for dermatology and eye care, education through sponsorship programs for their children with albinism, and support and facilitation of the mamas' groups so valued by mothers in this study (Objective 2). Mothers explained that, by and large, they were not given necessary information upon the birth of their child(ren) about the condition of albinism. This remains an area of grave concern: If mothers are equipped early with knowledge and tools to protect their children from skin cancer and barriers related to low vision, their health and well-being will begin in the right trajectory. Mothers bear the burden of stigma,

discrimination, and violence against their children with albinism (Objective 3). As children of single-mother homes are more vulnerable to attacks and abduction, mothers spoke of the stress and anxiety around attempts to ensure their children remain safe when out of their presence (e.g., while at school, walking to and from school, at home while mothers are working). Finally, mothers interviewed spoke of needing capital in order to start businesses individually or collectively with other women as a path out of poverty, or even towards living in a safe home. Mothers spoke of the negative views of society as barriers to such pathways, prohibitive of employment and full engagement/participation in the community. They spoke of mamas' groups as the only space where they experienced being fully embraced and supported. Mamas' groups offered the social and economic supports they have not found elsewhere (Objective 4).

Conclusions of the Study

She really wishes that you continue visiting the women and listening to them and listening to their challenges as we all come up with a collective solution to address our challenges.

– Mother, Sharing Circle-8

The following conclusions are generated on the basis of this study's findings.

1. Mothers impacted by albinism face various and compounding factors that influence their own and their child(ren)'s health and well-being, access to services, and parenting. NGOs such as *NGO-1* and *NGO-2* currently provide the vital services that have improved the lives of persons with albinism. Mamas' groups remain the only mother-specific service, and they have yet to be scaled up.

2. Mothers experience stigma and discrimination immediately upon delivery of their child with albinism which continues across the lifespan of their child(ren). Many of their human rights are threatened, including safety and security, access to health and education, access to employment, and support of their right to parenting. In the face of a multiplicity of human rights violations, mothers are surviving and asking more from their environments.

3. Given resources and support, mothers' resilience is realized in a way that moves their experience from one of survival to well-being and family flourishing. This occurs in the presence of targeted, multi-sectoral supports that account for their intersectional experience: social, health and social services, education, and economic.

4. This study highlights that the voices of mothers impacted by albinism are too often silent in current policies and practices aimed to serve those impacted by albinism in Tanzania. Mothers are the experts in their own lives and know what supports and resources would best benefit them and their children in the context of albinism. Counter to the assumption that mothers abandon their children or do not wish to be a part of their life, every mother in this study communicated a strong desire to mother their child(ren) with albinism despite the circumstances they are thrust into as a result. All barriers to accessing their children and providing the key function of parenting need to be removed. This study revealed that there is no replacement for the role of the mother and that this is deeply experienced by women and their children who have been separated—even in the context of ensuring safety and security, the answer cannot be family separation.

Recommendations

The following recommendations reflect the key findings in this study. Through a nursing lens, relevant recommendations are offered at the policy, NGO/CSO, health and social services, research, and leadership levels.

Policy

At the policy level, much direction can be found following the UN Sustainable Development Goals (SDGs) for 2030. Government and policymakers should ground their next steps within this framework. The SDGs provide an accountability tool for broader government and policymakers within Tanzania, offering a way to measure, assess, and advance the human rights of mothers and their children for equitable access to health care and gender equality.

All policy efforts should begin with the perspectives of mothers impacted by albinism themselves. As a largely untapped source of knowledge and expertise in their own lives and the situations of their children, their voices should be involved in all stages of policy development and implantation. Embedded within policies regarding these mothers and their children should be considerations regarding how they will positively impact their lives, livelihoods, and well-being.

Policy related to health and social services should engage nursing leadership within Tanzania. Nurses, as central professionals providing health care to women and children, have expertise that could provide policy makers with key information as to gaps within nursing education and practice that perpetuate unethical care of mothers and their children born with albinism. As global leaders in health policy, nursing scholarship and leadership is needed to develop relevant, sustainable policy formation impacting the profession and the patients in its care.

Civil Society and Non-Governmental Organizations

Mamas' groups need to be supported and scaled up. These groups provide invaluable social support, sisterhood and economic resourcing and may be the first point of contact for mothers with similar life experiences, as reflected numerous times by participants (Chapter Five). The groups also provide a basic level of skill training to support their economic livelihood, which impacts their family as a whole. The findings of this study revealed that these groups are the sole support for mothers impacted by albinism in a number of cases.

These mamas' groups represent an access point for stakeholders to engage women impacted by albinism to seek their expertise in their own lives and that of their children. Women identified what they needed to address the poverty they confront: capital to grow their businesses, both individual and collective. Groups were very entrepreneurial. For example, one group shared their idea for starting a mill business together—aware that they would be able to produce more grain as a group than individually. Business acumen exists; fostering this with further resources could be a way in which CSOs/NGOs could scale up their support of mothers impacted. As mothers are resourced and supported, they could be involved in advocacy work. This involvement could be empowering for women who are largely silenced and marginalized. Opportunities for them to be a part of creating change in their own communities and society further movement towards well-being and family flourishing.

CSOs and NGOs are central to community education regarding albinism. Both *NGO-1* and *NGO-2* provide extensive education to community leadership, healthcare professionals, educators, faith leaders, and government officials. This education should be supported by the government and scaled up to continue reaching stakeholders throughout Tanzania, particularly in

healthcare facilities, clinics, and among villages where traditional midwives or family members deliver babies in their communities.

Mobile clinics remain a key source of health services for families impacted by albinism, including dermatology and eye care clinics. Mothers requested an ease of accessing such clinics, including knowing in advance when and where they are to be held. Mothers requested that if not all of their children with albinism are sponsored in a boarding school where such mobile clinics are regularly scheduled and well attended, that they be notified and invited to bring other children they have with albinism to receive the care at the same time. It is noted that both NGOs in this study make great efforts to ensure that all children and families impacted by albinism are notified and included in these clinics. The challenge of ensuring information is well communicated in the context of Tanzania is difficult given various barriers, most obviously a lack of infrastructure and geographical distance between villages.

Finally, a commitment to move towards a family-centred approach to sponsorship is necessary. This would be in line with valuing the central role of family, key within the sub-Saharan context (Hudson-Weems, 2019). Mothers and children must be viewed as one unit: not to be separated, but to be supported as a dyad. Particularly in the transition towards family sponsorship, attention must be directed towards reducing barriers to accessing children currently sponsored in boarding schools. As discussed in Chapter Five, mothers face various roadblocks as they attempt to visit their children sponsored in some boarding schools: transportation/accommodation costs, obtaining documents from government offices (local and district leadership) proving they are the child's parent, the inability to communicate directly with school administration or staff regarding the academic and social progress of their child(ren), and

lengthy separation from their children. While safety and security must be ensured in these

schools, parental rights must not be infringed upon per the African Charter on the Rights and

Welfare of the Child (1990) (Articles 19 and 20 specifically) of which Tanzania is a signatory.

Health and Social Services

As Waithera aptly argues, "it all starts in the delivery room" (personal communication,

January 2019). From the moment a baby with albinism is identified in the birth canal by a nurse,

midwife, physician, or lay midwife in the woman's home, the journey for mother and babe

begins. This represents an opportunity to begin the journey of mothering a child with albinism

accepted, well informed, and empowered. Unfortunately, for the vast majority of women, as

confirmed in our research, these experiences are typically the antithesis of this with healthcare

practitioners often uninformed about albinism themselves. Interviews revealed that there is

progress being made in particular hospitals and regions, but confirmed that more education for

staff was needed to ensure that mothers and their families leave the hospital knowing more about

albinism and how to care for their child. As a point of priority, spouses/partners must be included

in hospital discharge teaching regarding albinism, including the genetic component.

Healthcare leadership from policy, education, and regulatory sectors must ensure that all

healthcare providers, including traditional midwives, are well equipped to respond to deliveries

of children with albinism. Such stakeholders should partner with NGOs and CSOs in delivering

such education, as this study identified the effectiveness of persons with albinism themselves

delivering this education. In terms of trajectory, prioritizing healthcare professionals in

engagement and education strategies aimed at engaging entire families from the point of delivery

is quintessential. Upstream approaches would ensure that women who deliver a baby with

albinism are immediately embraced with wraparound support and services. Such services would

include nurses and physicians who provide incremental information to mothers and fathers upon

delivery; social workers who meet families in hospital and follow up in their homes; pharmacies

providing regular access to free sunscreen; and community clinics providing skin assessments

and vision care.

The role of social services in family reunification is of vital importance. As documented

in other reports, mothers and key stakeholders in this study emphasized that the separation of

children from their families carries long-term effects. The loss of parenting and attachment

surfaced various times in interviews with both mothers and key informants (e.g., teachers and

social workers). Two recommendations that surfaced as priorities: reunification, when safe and

in the best interests of the child and minimizing barriers (as outlined in the section above) to

accessing their children when separation is required due to safety. The importance of

reunification exists not only for the child affected, but the mother who has been separated from

her child(ren).

Addressing trauma on the individual and family level should also be allocated to social

services within Tanzania. This will require a large scaling up of resources in this sector of health

care. The trauma experienced by mothers affected by albinism takes multiple and repeated

forms, including stigma and discrimination, violence and threats to security, separation from

children, and abandonment by partners and family members. Therefore, access to counselling

and trauma support services that are culturally and contextually relevant is needed. The explicit

request for contextual, Afrocentric counseling and support surfaced with participants identifying

that Westerners need not apply.

Research

Further research related to the gendered nature of albinism is required to understand the

social context in which fathers disengage from their families and abandon their partners when

they deliver a child(ren) with albinism. Research on engaging fathers of children with albinism

to remain involved and supportive of their families is needed as single parenting in the

Tanzanian context is a key burden to mothers impacted. Further, within an African ontology, it

appears to be counter to values of family-centrality as well as deeply held religious beliefs (i.e.,

large numbers of the Tanzania population identify as Christian and Muslim).

Further research related to the experience of mothers impacted by albinism, including

mothers with albinism themselves, is needed. Indeed, future research related to albinism,

particularly children with albinism, should include the perspectives and experiences of mothers,

affirming the mother-child dyad. Applying Hudson-Weems' (2019) Africana Womanism as a

theoretical framework alongside a human rights lens within future research related to women

impacted by albinism would advance research literature rooted in Afrocentric values. To this

point, further research related to the interplay of resilience and the social environment in this

particular context of albinism is needed.

Concerning the role of nursing, globally, research related to how nursing can best support

persons with albinism would be useful in advocating for best practices for this marginalized,

minority group. Research should include how to implement albinism education in nursing

programs as well as in professional development with employers. As leaders in health care and a

profession that holds social justice, equity, and ethical care as central values, globally, nursing

research has an important role to play in advancing the human rights of persons with albinism

within our own profession. Driven by their voiced experiences and analysis of their own

situations, recommendations for nursing need to be articulated, exploring how we, as global

leaders in health care, can best promote the cause of mothers of children with albinism

globally—ensuring access to health and social services as well as health-related knowledge

associated with albinism. As mandated by the ICN, nurses have an important role to play in

responding to human rights violations and are responsible to raise a voice towards equitable

policy and practice (ICN, 2011, 2018).

Leadership

Government accountability and reconciliation with families impacted by albinism are

needed. The Tanzanian government response to violent attacks against children with albinism

failed to include key factors: the collection and safekeeping of key demographic information of

children brought to and housed in government holding centres; contact information for

parents/relatives; perspectives and explicit consent from parents; and, most important to the

current situation, plans for reuniting families and ensuring safety at home. Government officials

should have consulted families and engaged them in the process. While violence and risks to

security are the root cause of family separation, the government response was poorly planned

and chaotically executed. Accountability is necessary to rebuild trust and ensure that the solution

for protecting persons with albinism in the country does not continue to be segregation and

isolation.

This gap left by a troubling government response to the crisis in 2008 has been filled by

CSOs and NGOs like those mentioned in this study. While imperfect, the response of child

sponsorship was necessary and, without a doubt, has provided better care and education for

children with albinism. What remains necessary to reconcile, however, is how the original

government response and subsequent intervention by NGOs unwittingly further compromised

particular rights of the child and parent. Separation as the answer, particularly when there is no

formal consent given by parents, is troubling and must continue to be addressed. This work can

begin by engaging mothers in all levels of programming and implementation: ensuring a family-

centred approach in framing the work, programming, and values at the organizational level.

Indeed, what happens if we shift the narrative to the voice of mothers who know what their

children need?

The work of Ero in her UN mandate has advanced the cause of persons with albinism

worldwide. The UN and Pan African initiatives should remain engaged, listening to the voices of

mothers impacted. Their work should continue to be intersectoral, engaging various stakeholders,

including building capacity at the local level with community leadership and beyond at the

regional, national and international levels.

Chapter Summary

This chapter provided concluding remarks, including a summary of the study,

demonstrating how this focused critical ethnography explored the experience of mothering

children with albinism in Tanzania. Key conclusions drawn reflect the various compounding

factors influencing the health and well-being of mothers and their child(ren) with albinism,

including access to services; the stigma and discrimination that mothers face the moment they

deliver a child with albinism; the minimal resources and supports available; and the importance

of mothers' voices in the narratives of albinism. Relevant recommendations were provided from

a nursing lens, including those for policy, NGOs/CSOs, health and social services, education,

research, and leadership. This study, in concert with the voices of all of the mothers impacted by

albinism involved, argues for and provides clear rationale for a more inclusive society with

services that better empower and support impacted women and their children to thrive.

Figure 15. The "kitchen" off of a main house where women roast foods on an open wood fire.

With laundry hanging up alongside this structure, this photo depicts some of the daily physical

work mothers are engaged in in some parts of Tanzania.

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Appendix A: Literature Review Search Strategy

Inclusion/Exclusion Criteria:

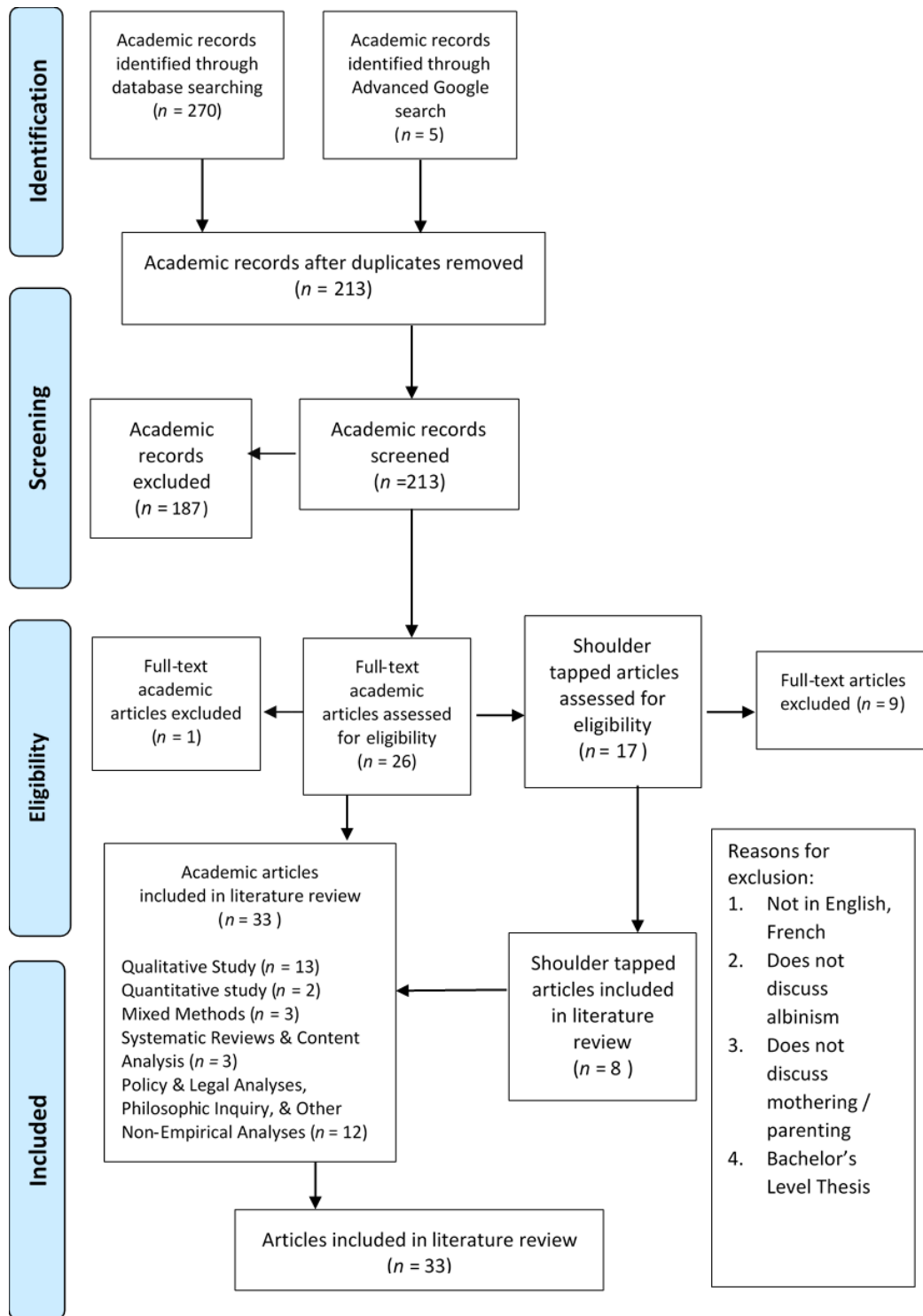| Inclusion	Peer Reviewed; English, French; Masters or PhD Thesis; Substantive discussion on concept of mothering/child rearing (minimum of 100 words); Grey Lit and Other (Book by Kromberg)
Exclusion	Not peer reviewed; Not in specified langlue; no substantive discussion on albinism and mothering/parenting; Bachelor's level thesis

Keyword Search Strings

	AND		AND		AND	
Africa* OR Tanzania* OR Sub-Sahara* OR Malawi OR Zimbabw*		(Child* OR infant OR baby OR babies OR adolescen* OR youth)		(albinism OR albino)		Mother* OR parent* OR rais*

Google Scholar: (Will screen first 4 pages of results only)

	Total Results	Results
1. albino children tanzania parent	2,180	**2**
2. albino children tanzania mother	2,050	**1 (Lynch Lund Massah (2014) *noted Jan 19*)**
3. albinism children tanzania mother	848	1 (~~Maybe~~YES 19Jan2019: Butler-Jones, C. (2013). *The impact of resilience on help-seeking behavior among people with albinism in tanzania* (Doctoral dissertation, The Chicago School of Professional Psychology).)
4. albinism children tanzania parent	1,140	**1**
	Duplicates:	**2**
	YES:	**3**

Search #1	Search Completed for Articles up to February 2020	
Database	**Notes**	**Total Results**
Library One Search (25 Aug 2018)	Using short albinism string (lost key Kromberg article using long albinism string) & using "Africa OR Tanzania OR Sub-Saharan Africa OR Malawi"; RIS files emailed to my account for upload into EndNote	74
CINAHL	4 with search as above; 1 using long albinism string	4
CINAHL Subject Headings	(MH "Albinism/ED/EC/EI/HI/LJ/MO/NU/OG/PF/RH") AND (MH "Mothers") AND (MH "Africa") AND (MH "Child") ; also tried (MH "Albinism/ED/EC/EI/HI/LJ/MO/NU/OG/PF/RH") AND (MH "Mothers") AND (MH "Tanzania") AND (MH "Child")→ will use "Africa" for broader results? (both saved to RIS)	90
MEDLINE	(Africa OR Tanzania OR Sub-Saharan Africa OR Malawi) AND ((Child* OR infant OR baby OR babies OR adolescen* OR youth)) AND ((albinism OR albino)) AND (Mother* OR parent* OR rais*)	11
PsycInfo	Africa OR Tanzania OR Sub-Saharan Africa OR Malawi) AND (albinism OR albino) AND (Mother* OR parent* OR rais*) AND (Child* OR infant OR baby OR babies OR adolescen* OR youth)	4
PsycInfo Thesaurus	((DE "Parenting") OR (DE "Mothers") OR (DE "Childrearing Attitudes")) AND (DE "Albinism") AND (DE "African Cultural Groups") → *"initial query did not yield results"…message	73
Academic Search Complete	Africa OR Tanzania OR Sub-Saharan Africa OR Malawi) AND (Child* OR infant OR baby OR babies OR adolescen* OR youth) AND (Mother* OR parent* OR rais*) AND (albinism OR albino	3
Academic Search Complete- Subject Headings	(DE "ALBINOS & albinism") AND ((DE "MOTHERS") OR (DE "CHILD rearing")) AND (DE "CHILDREN") AND (DE "TANZANIANS")	8
EMBASE	Africa* OR Tanzania* OR Malawi* OR Zimbabw* OR Sub-Saharan* AND ((Child* OR infant OR baby OR babies OR adolescen* OR youth)) AND ((albinism OR albino)) AND (Mother* OR parent* OR rais*)	3
Total Before Duplicates Removed:		*270*
Duplicates		*60*
Total After Dups Removed:		*210*
		No: 187 +1
		Yes: 22

Appendix B: PRISMA Diagram of Screening Methodology (Moher et al., 2009)

Appendix C: Sample of Literature Review Matrix

Article	Geographical region of focus	Focus of Article	Method	Sample -- participants
Aquaron, R., Djatou, M., & Kamdem, L. (2009). Sociocultural aspects of albinism in Sub-Saharan Africa: Mutilations and ritual murders committed in East Africa (Burundi and Tanzania). *Medecine Tropicale: Revue Du Corps De Sante Colonial, 69*(5), 449-453.	Burundi, Cameroon, Tanzania	Report that "presents an overview of the many sociocultural prejudices confronting albinos and their parents in Sub-Sarharan Africa at each stage of life (infancy, adolescence, and adulthood)" (p. 449).	Non-empirical Analysis	n/a
Baker, C., Lund, P., Nyathi, R., & Taylor, J. (2010). The myths surrounding people with albinism in South Africa and Zimbabwe. *Journal of African Cultural Studies, 22*(2), 169-181.	South Africa and Zimbabwe	Examines how continued myth and belief surrounding albinism impacts the personal identity and social acceptance of PWAs	Non-empirical (Pathography)	n/a
Braathen, S. H., & Ingstad, B. (2006). Albinism in Malawi: Knowledge and beliefs from an African setting. *Disability & Society, 21*(6), 599-611. doi:10.1080/09687590600918081	Malawi	In Malawi, what knowledge, beliefs, and behaviors do PWA and their family members have about albinism?	Qualitative	(n = 25) PWA and their family members
Bradbury-Jones, C., Ogik, P., Betts, J., Taylor, J., & Lund, P. (2018). Beliefs about people with albinism in Uganda: A qualitative study using the common-sense model. *PloS One, 13*(10): e0205774	Uganda	Explored "the links between beliefs, myths, traditions and positive/negative attitudes that surround people with albinism in Uganda" (p. 1); inside and outside perspectives	Qualitative	(n = 73)

Brocco, G. (2015). Labeling albinism: Language and discourse surrounding people with albinism in Tanzania. *Disability & Society, 30*(8), 1143-1157. doi:10.1080/09687599.2015.1075869	Tanzania	Language and marginalization of persons with albinism in Tanzania	Qualitative: Ethnography	(n = 28) PWA in villages in Kilolo district, Tanzania. 13 males, 15 females. Ages: 7-70
Brocco, G. (2016). Albinism, stigma, subjectivity and global-local discourses in Tanzania. *Anthropology & Medicine, 23*(3), 229-243. doi:10.1080/13648470.2016.1184009	Tanzania	"This paper examines the subjectivity of a 28-year -old Tanzanian woman with albinism in relation to both stigmatization and acceptance within her family and community settings" (p. 230).	Qualitative: Ethnography	(n = 8) 28 year old woman and 7 other informants with the congenital condition
Bryceson, D. F., Jønsson, J. B., & Sherrington, R. (2010). Miners' magic: Artisanal mining, the albino fetish and murder in Tanzania. *The Journal of Modern African Studies, 48*(3), 353-382	Tanzania	"Through the concept of fetish creation, this article interrogates the agency of those involved in the murders: the miners who purchase the albino charms, the *waganga* healers…who sell the charms, and the albino murder victims" (p. 354); explores the meso, macro, micro context in which murders are taking place	Non-empirical Analysis	n/a

Burke, J., Kaijage, T. J., & John-Langba, J. (2014). Media analysis of albino killings in Tanzania: A social work and human rights perspective. *Ethics and Social Welfare, 8*(2), 117-134. doi:10.1080/17496535.2014.895398	Tanzania	"The aim is to explore the involvement of various social actors in violating, or protecting, the right of people with albinism, as well as strategies of preventing and responding to the violence. These explorations are guided by a human rights framework" (p. 118); What is the role of social work(ers) in addressing the human rights violations of PWA in Tanzania?	Content Analysis	(n = 274); media analysis of 121 English articles and 153 Swahili articles
Butler-Jones, C. (2013). *The impact of resilience on help-seeking behavior among people with albinism in Tanzania* (Doctoral dissertation). Retrieved from ProQuest LLC. (UMI 3599490)	Tanzania	Resilience and help-seeking among women with albinism	Qualitative	n=25 (women with albinism)
Corn, A. L., & Lusk, K. E. (2018a). An analysis of parents' reports on educational services for their children with albinism. *Journal of Visual Impairment & Blindness, 112*(6), 667-682.	USA	Explores information and services related to the education of children with albinism from the perspective of parents of children with albinism in the USA	Quantitative	(n = 223)
Corn, A. L., & Lusk, K. E. (2018b). Reports from parents about medical and low vision services for their children with albinism: An analysis. *Journal of Visual Impairment & Blindness, 112*(6), 655-666.	USA	Explores information and services related to medical care and low vision care from the perspective of parents of children with albinism in the USA	Quantitative	(n = 223)

Cruz-Inigo, A. E., Ladizinski, B., & Sethi, A. (2011). Albinism in Africa: Stigma, slaughter and awareness campaigns. *Dermatologic Clinics, 29*(1), 79-87. doi:10.1016/j.det.2010.08.015	sub-Saharan Africa	Aims to draw attention to the dire situation of PWAs in sub-Saharan Africa, heavy focus on access to health care and preventative measures re: skin CA.; What do PWAs face in sub-Saharan Africa in terms of their safety/security, health, education, employment and what is the role of the national and international community?	Non-empirical Analysis	n/a
Ehlers, V. (2002). Republic of South Africa: Policies and politics guide nurses' application of genetic technology in public health settings. *Policy, Politics & Nursing Practice, 3*(2), 149-159.	South Africa	Examines the impact of policy and political changes to genetic services provided in South Africa since 1994. Advocates for education and system wide support for genetic nurses to educate mothers and families re: various genetic conditions including albinism	Policy Analysis	n/a
Estrada-Hernández, N., & Harper, D. C. (2007). Research on psychological and personal aspects of albinism: A critical review. *Rehabilitation Psychology, 52*(3), 263-271. doi:10.1037/0090-5550.52.3.263	Global (Africa, Panama, Israel, USA, Canada)	"...a critical review of the research literature, examining factors associated with adaptation to the albinism condition" (p. 263).; Psychological and personal adaptation	Systematic Review	n/a

Franklin, A., Lund, P., Bradbury-Jones, C., & Taylor, J. (2018). Children with albinism in African regions: Their rights to 'being' and 'doing'. *BMC International Health & Human Rights, 18*, 1-8. doi:10.1186/s12914-018-0144-8	Africa	Focus on Children and young people with albinism; Using Thomas's social-relational model of disability alongside discussion regarding human rights, can we "address the lacuna surrounding the psychosocial and daily experiences of [PWA]" (p. 1)?	Non-empirical Analysis	n/a
Gaigher, R. J., Lund, P. M., & Makuya, E. (2002). A sociological study of children with albinism at a special school in the Limpopo province. *Curationis, 25*(4), 4-11.	South Africa	Explores the social context of children with albinism and examines how the condition effects self, relationship to others, and education / employment etc.	Mixed methods	(n = 32)
Imafidon, E. (2017). Dealing with the other between the ethical and the moral: Albinism on the African continent. *Theoretical Medicine & Bioethics, 38*(2), 163-177. doi:10.1007/s11017-017-9403-2	Africa	"To explore how the uneasiness and consequent indifference about the other play out on the African continent with a particular attention to albinism" (p. 164); Imafidon seeks to show "how the African community has managed to establish and promote ontological and normative ideologies that help sustain the (ill) treatment of persons with albinism as an other" (p. 164)	Philosophic Inquiry	n/a

Kiishweko, R. R. (2017). *Albinism in Tanzanian higher education: A case study* (Unpublished doctoral dissertation). University of Sussex, UK. Retrieved from http://sro.sussex.ac.uk/id/eprint/67375/1/Kiishweko%2C%20Rose%20Rutagemwa.pdf	Tanzania	Experience of students with albinism in Higher Education in Tanzania	Qualitative	(n = 35)
Kromberg (2017). Psychosocial and cultural aspects of albinism. In J. Kromberg & P. Manga (Eds.) *Albinism in Africa: Historical, geographic, medical, genetic, and psychosocial aspects* (pp. 172-198). London: Elsevier Academic Press.	Africa	Psychosocial and cultural aspects of albinism (related to self-concept and social relations with others)	Non-empirical Analysis of the Literature	n/a
Kromberg, J. G., Zwane, E. M., & Jenkins, T. (1987). The response of black mothers to the birth of an albino infant. *American Journal Of Diseases Of Children (1960), 141*(8), 911-916.	South Africa	Response of "black mothers" to their albino infants over 15 months; what is the response of a "black mother to her newborn albino infant"? (p. 911). The study followed the dyad until the babe was 15 months	Mixed methods	(n = 30) mothers of children with and without albinism
Lund, P. M., & Gaigher, R. (2002). A health intervention programme for children with albinism at a special school in South Africa. *Health Education Research, 17*(3), 365-372.	South Africa	Explored the physical, social-psychological, and educational experiences / concerns of children with albinism	Mixed Methods: Questionnaire and interview	(n = 38) children with albinism

Lynch, P., Lund, P., Massah, B. (2014). Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi. *International Journal of Educational Development*, *39***,** 216-224.	Malawi	Educational inclusion of children with albinism (focus of visual impairment)	Qualitative: Participatory Study	(n = 122) Education professionals, children with albinism and their families
Masanja, M. & Magembe, K. (2015). Power of stigma against households' efforts to maintain households' wellbeing among households with albinos in Tanzania. *International Journal of Education and Research, 3*(11), 95-108.	Tanzania	Stigma and household well-being for households impacted by albinism in Tanzania	Qualitative	(n = 10) households
Morris, M., Glass, M., Wessels, T.-M., & Kromberg, J. (2015). Mothers' Experiences of Genetic Counselling in Johannesburg, South Africa. *Journal of Genetic Counseling, 24*(1), 158-168. doi:10.1007/s10897-014-9748-x	South Africa	Explore how mothers of children with Down Syndrome, OCA and Hemophilia B experience genetic counselling	Qualitative	(n = 13) mothers of children with Down Syndrome, OCA or Hemophilia B

Mswela, M. M. (2019). Tagging and tracking of persons with albinism: A reflection of some critical human rights and ethical issues arising from the use of the global positioning system (GPS) as part of a solution to cracking down on violent crimes against persons with albinism. *PER: Potchefstroomse Elektroniese Regsblad, 22(1), 1-27.*	South Africa, Malawi	Explores the ethical and legal concerns of using GPS tracking methods to protect PWAs in South Africa from violent attacks.	Legal Analysis	n/a
Mulemi, B. A., & Ndolo, U. (2014). *Albinism, witchcraft, and superstition in east Africa: Exploration of bio-cultural exclusion and livelihood vulnerability* (Unpublished report) [PDF]. Nairobi, KE: The Catholic University of Eastern Africa.	Tanzania	"This study explores and examines the implications of witchcraft beliefs and superstition for livelihood security of PWA" (p. vi).	Qualitative, ethnography	(n = 50)
Pooe-Monyemore, M. B. (2007). *A model for enhancement of self-concept of people with albinism*. (D.Litt. et Phil.), University of South Africa (South Africa), Retrieved from https://ezproxy.student.twu.ca/login?url=http://search.ebscohost.com/login.aspx?direct=true&db=ccm&AN=109851170&site=ehost-live Available from EBSCOhost ccm database.	Gauteng Province in South Africa	Self-concept of people with oculocutaneous albinism	Qualitative	(n = 15) consisting of twelve females and three males with albinism, aged between 18 and 48

Pooe-Monyemore, M. B. J., Mavundla, T. R., & Christianson, A. L. (2012). The experience of people with oculocutaneous albinism. *Health SA Gesondheid, 17*(1), 1-8. doi:10.4102/hsag.v17i1.592	South Africa	Psycho-social experiences of persons with albinism	Qualitative	(n = 15)
Reimer-Kirkham, S., Astle, B., Ero, I., Panchuk, K., Dixon, D. (2019). The influence of spiritual and cultural practices on health and healthcare of persons with albinism: A scoping review. *Disability & Society, 34*(5), 747-774.	Global	"To establish the current state of knowledge on albinism, spiritual and cultural practices, and implications for health and health services" (p. 747).	Scoping Review	(n = 40) articles reviewed
Shewedi, S. E. (2011). *Parents' negative attitude towards the education of their special needs children in Tanzania: The case study of Moshi selected integrated primary schools* (Unpublished master's thesis). University of Dar es Salaam, Tanzania.	Tanzania	Explored parents' attitudes towards educating their children with special needs (including albinism). Data collected from parents and educators	Qualitative	(n = 163)
Taylor, J. S., & Lund, P. (2008). Experiences of a feasibility study of children with albinism in Zimbabwe: A discussion paper. *International Journal of Nursing Studies, 45*(8), 1247-1256.	Zimbabwe	Explored the overall feasibility of "undertaking a study on children with albinism [specifically, their psychosocial and welfare needs] in Zimbabwe…" (p. 1247).	Feasibility study	n/a

Taylor, J., Bradbury-Jones, C., & Lund, P. (2019). Witchcraft-related abuse and murder of children with albinism in sub-Saharan Africa: A conceptual review. *Child Abuse Review*, *28*(1), 13-26. doi: 10.1002/car.2549	sub-Saharan Africa	Conceptual review of research related to witchcraft-related abuse and murder of children with albinism; explores the use of an integrated framework of otherness, watchfulness, and agency	Conceptual Review of Literature	n/a
Duri, F. P. T., & Makama, A. (2018). Disabilities and human insecurities: Women and oculocutaneous albinism in post-colonial Zimbabwe. In M. Mawere & A. Nhemachena (Eds.), *Rethinking securities in an emergent technoscientific new world order: Retracing the contours for Africa's hi-jacked futures* (pp. 77–110). Bamenda, CM: Langaa RPCIG.	Zimbabwe	Explores the experiences of Zimbabwean women with albinism as "one of the most vulnerable sections of the population" (pp. 77)	Book Chapter-analysis of literature	n/a

Appendix D: NVIVO Literature Review Codebook

Node Name	Description	Files	References
A. Mothering & Albinism		0	0
A1. Experience of women with albinism	Primary concerns and experiences	5	12
A2. Experience of girls with albinism		2	3
A3. Pregnancy (experience) of woman with albinism		0	0
A4. Delivery of child with albinism		9	16
A5. Post Partum period of mother who has a baby with albinism		1	5
A6. Partner Spouse Support		5	14
A7. Experience of Mothers	Mother's perspective	12	30
B. Support- Family, Community, Gov't, NGOs		0	0
B1. Family dynamics (how mom and babe are treated by family and in-laws)		12	33
B2. Receptiveness in community	How does the home community receive this dyad	6	10
B3. Community Support	What kind of supports do the community provide? Cultural practices and/or intentional supports	3	4
B4. Government support and resources		3	4
B5. NGO & CSO support and resources		2	4
C. Influences on the experiences of mothering children with albinism		0	0

C1. Social Determinants of Health		0	0
C1a. Poverty		6	8
C1b. Gender		7	11
C1c. Disablism (discrimination)		8	14
C1d. Sociocultural views (myth, stigma)		7	17
C1e. Physical Location	rural vs urban; country of origin; neighbourhood,	3	6
C1f. Availability of H & SS		3	6
C1g. Education		10	14
C1h. Employment		3	7
C2. Social constructions of womanhood (African Womanism)		4	7
C3. Faith, Spirituality, Religion	Belief in higher power- linked with resilience/coping/way of explaining albinism as will of God vs. harmful myth	4	9
D. Access to H & SS		0	0
D1. Community Lead or Grassroots Level		1	1
D2. Government		6	6
D3. NGO & CSO		4	6
D4. Health related knowledge and education (access to)		9	16
E. Threats to HR and Health		0	0
E1. Myth-Stigma & Health		7	12
E2. Discrimination & Health		5	6

E3. Gender Specific Threats & Health		7	10
E4. Violence and Health		6	15
F. Everyday Lives of Mothers of Children with Albinism		0	0
F1. Primary Concerns	primary concerns of mothers who are caring for a child(ren) with albinism	3	3
F2. Parenting Strategies		5	6
F3. Parenting Struggles		8	22

Appendix E: Interview Guides (English and Kiswahili)

INTERVIEW GUIDE #1 (Sample Questions)

KEY INFORMANTS and COMMUNITY MEMBERS

1. In what ways have you engaged the experiences of women with children, who have albinism? or mothers with albinism, in your work? (ask for story)

2. From your experience working with persons with albinism, what do you feel are the primary concerns of mothers affected by albinism?

3. What have you noticed about parenting strategies employed by these mothers?

4. How does having a child with albinism, or having albinism themselves, fit in with other life circumstances of these women?

5. How do mothers impacted by albinism access community services?

MWONGOZO WA MAHOJIANO #1 (MASWALI YA SAMPULI)

KWA WATOA HABARI WAKUU NA WANAJAMII

Madhumuni ya mradi huu ni kuelewa namna malezi na ualbino yanahusiana, hasa kwa kina mama ualbino au walio na watoto wenye ualbino

1. ni kwa namna gani umeweza kushirikisha uzoefu wa kina mama walio na ualbino au kina mama walio na watoto wenye ualbino kazini ?

2. Kutokana na tajiriba yako ya kufanya kazi na watu wenye ualbino ni maswala yapi ya kimsingi yanawaathiri?

3. Ni mikakati ipi ya malezi imewekwa na kina mama hawa?

4. Je kina mama hawa wenye ualbino au wenye watoto wenye ualbino wanajitosheleza vipi kwenye maisha ya kina mama?

5. Je kina mama wanaoathiriwa na ualbino hupata hudumma za kijamii namna gani

INTERVIEW GUIDE #2 (Sample Questions)

MOTHERS OF CHILDREN WITH ALBINISM

1. Tell me about your family.

2. What is it like having a child with albinism?

3. Did you know that you might have a child with albinism? Maybe because a relative on your side or your husband's side?

4. How did you feel when you learnt that your baby had albinism? What were the first few days like?

5. What was your experience during the first few months of mothering a child with albinism?

6. Can you describe the day-to-day care of your child with albinism [use child's name]? [if they have other children:] How is raising [child's name] different from parenting your other children?

7. I am interested in how being a mother (or a woman) of a child with albinism might be different than for a father (or a man). With a child with albinism, how are the father's experiences different from the mother?

8. Tell me about any beliefs within your community or family about albinism, such as why it happens or what it means.

9. What resources (or help in the community) have helped you care for your child with albinism?

10. What would help support mothers of children with albinism? Is there something that has been helpful in your experience? Anything that has been unhelpful?

MWONGOZO WA MAHOJIANO #2 (MASWALI YA SAMPULI)

KINA MAMAWENYE WATOTO WENYE UALBINO

1. Nieleze kuhusu familia yako?

2. Je maisha yako vipi kutokana na kumpata mtoto Mwenye ualbino?

3. Je ulikisia kwamba waweza kumpata motto Mwenye ualbino aidha kutokana na kuwa na jamma Mwenye ualbino au upande wa kina Bwana?

4. Ulihisi vipi ulipogundua kuwa mtoto wako ana ualbino? Siku za mwanzo mwanzo zilikuwa vipi?

5. Ni yapi uliyopata kuyajua miezi ya kwanza ya malezi kwa mtoto Mwenye ualbino?

6. Je waweza fafanua kwa kina malezi ya siku kwa siku ya mtoto wako Mwenye ualbino (mtaje jina). (iwapo ana watoto wengine). Ni tofauti gani iliyopo kati ya malezi ya mtoto huyu na wengine?

7. Ningependa kujua tofauti ya mama wa mtoto ualbino na baba. Je ni yapi anayokumbuna nayo baba wa mtoto ualbino ?

8. Nieleze miiko na imani zilizoko katika jamii na familia yako kuhusu ualbino ; kwa mfano mbona au inatokeaje?

9. Ni rasilimali (au msaada upi kutoka kwa jamii) umeweza kupata kutoka kwa jamii kulea mtoto wako Mwenye ualbino?

10. Je ni msaada upi wameweza kupata kina mama wenye watoto wenye ualbino? Je kutokana na maisha yako, je kunalo umeweza kunufaika nalo? Je ni lipi haujaweza kunufaiko nalo?

INTERVIEW GUIDE #3 (Sample Questions)

MOTHERS WITH ALBINISM

1. Tell me about your family.

2. What is it like being a mother with albinism? How does albinism affect your parenting? Your family life? (ask for story)

3. What are your main worries as a mother with albinism? How do you handle these worries?

4. I am interested in how being a mother (or a woman) with albinism might be different than for a father (or a man) with albinism. How are the father's experiences different from the mother?

5. Tell me about any beliefs within your community or family about albinism, such as why it happens or what it means.

6. What resources (or help in the community) have helped you live with albinism?

7. What would help support mothers with albinism?

MWONGOZO WA MAHOJIANO #3 (MASWALI YA SAMPULI)

KINA MAMA WENYE UALBINO

1. Nieleze kuhusu familia yako.

2. Je I vipi kuwa mama Mwenye ualbino? Yaathiri aje malezi yako? Na maisha ya familia je? (muulize akupe hadithi yake)

3. Ni wasiiwasi au mashaka yepi makuu unayoyapitia kama mama Mwenye ualbino? Je wayatatua vipi?

4. Ningependa kujua tofauti ya maisha ya mama mwenye ualbino Mwenye na baba Mwenye ualbino. Je ni nini kilicho tofauti katika maisha ya mama na baba Mwenye ualbino?

5. Nieleze miiko na imani zilizoko katika jamii na familia yako kuhusu ualbino; kwa mfano mbona au inatokeaje?

6. Je Ni rasilimali (au msaada) upi umeweza kupokea kutoka kwa jamii ambao umekusaidia kuishi na ualbino?

7. Ni nini kinachoweza kusaidia kudhamini kina mama wenye ualbino?

Appendix F: Confidentiality Agreement – Transcriptionist

INSPIRING HEARTS & MINDS

TRINITY WESTERN UNIVERSITY | SCHOOL OF NURSING

CONFIDENTIALITY AGREEMENT – TRANSCRIPTIONIST

Exploring the Mothering Experience of Women Who Have Children with Albinism

Emma Strobell RN, BScN
Principle Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

You have agreed to participate in this study by transcribing interview materials.

To ensure you protect **CONFIDENTIALITY** in this study, you agree to translate any names of persons or institutions you encounter during transcription into initials. In addition, you will not share any information from the research materials to any persons or agencies.

All research materials will be kept secure in a locked cabinet or drawer while in my possession. You will erase all transcription materials from the hard drive of your computer once you have transferred them to the principal investigator.

Should you have any questions or concerns, you can contact the PI by phone or email. If you need to speak with the PI's thesis supervisors, you can contact Dr. Sheryl Reimer-Kirkham and/or Dr. Barbara Astle by email at Sheryl.kirkham@twu.ca or barbara.astle@twu.ca.

If you have any concerns about your treatment or rights as a research participant, you may contact Elizabeth Kreiter in the Office of Research, Trinity Western University at 604-513-2167 or researchethicsboard@twu.ca.

You have discussed these requirements with the researcher, Emma Strobell, and have received a copy of this consent form.

_____   Transcriptionist Signature

_____   Transcriptionist (Printed Name)

_____   Date

7600 GLOVER ROAD LANGLEY, BC CANADA V2Y 1Y1   T: 604.888.7511   TF: 1.888.468.6898   **TWU.CA**

Appendix G: Confidentiality Agreement – Interpreter

INSPIRING HEARTS & MINDS

TRINITY WESTERN UNIVERSITY | SCHOOL OF NURSING

CONFIDENTIALITY AGREEMENT – INTERPRETER

Exploring the Mothering Experience of Women Who Have Children with Albinism

Emma Strobell RN, BScN
Principal Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

Sheryl Reimer-Kirkham RN, PhD
Supervisor and Professor
Trinity Western University School of Nursing
604 513 2121 ext. 3239| sheryl.kirkham@twu.ca

You have agreed to participate in this study by providing translation, interpretation, and cultural liaison services.

To ensure you protect **CONFIDENTIALITY** in this study, you agree to not share any information from the research materials or participant interviews to any persons or agencies. To ensure you protect the **QUALITY** of this study, you agree to provide direct interpretation/translation to the best of your ability to ensure the participant's original message is translated.

Should you have any questions or concerns, you can contact the PI by phone or email. If you need to speak with the PI's thesis supervisors, you can contact Dr. Sheryl Reimer-Kirkham and/or Dr. Barb Astle by email at sheryl.kirkham@twu.ca or barbara.astle@twu.ca.

If you have any concerns about your treatment or rights as a research participant, you may contact Elizabeth Kreiter in the Office of Research, Trinity Western University at 604-513-2167 or researchethicsboard@twu.ca.

You have discussed these requirements with the Principal Investigator, Emma Strobell, and have received a copy of this consent form.

_____   Interpreter Signature

_____   Interpreter (Printed Name)

_____   Date

Appendix H: Fieldnote Guide

1. Note date and time of day

2. Describe location (Where am I?/What is the geographic setting?/What is the location in relation to health and social services resources?/Is there transportation to and from location and between location and resources?/What objects stand out within the location?/What is my experience of being in the location?)

3. Who is present? (Who is not present?)

4. What is the participant's body language during fieldwork/interview/focus groups?

5. What is/are the participant(s) doing during the interview/focus group (actions)?

6. What emotions are being expressed or observed?

7. What agenda might they have (motivation for giving me their time and story)?

8. Any sense of what is happening locally: social, political tensions? Is there anything I suspect I may not be comprehending due to cultural differences or local particularities?

9. Describe my own sensory experience (noises, smells, what am I feeling in my body, (e.g., am I tired, anxious, sad, overwhelmed, etc.)

10. Describe my reactions (physical, mental, emotional) to topics discussed or to what was observed.

Appendix I: Sample of Fieldnotes

28 March 2019

Day 2- Dar

Awake at 0300. Sitting on the balcony to type these notes at 0430 with a cup of coffee.

It is now 0615 and I am watching the sunrise over the Indian Ocean. Breathtaking. Can the beauty of space and environment be hopeful in and of itself?

Male staff raking the beach volleyball court. Perhaps I don't know enough about beach life to judge the raking? It makes such little sense to me.

A morning jogger on the beach. I'm inspired!

0945: arrived at NGO office via Bajaji, Victor, we got a bit turned around and I realized just how dependent I am on both the driver and google maps!

1000: met with Director- friendly greeting.

Everyone keeps telling me that I am "most welcome"…feeling unsure when to voice that a meeting would be helpful. So I went ahead and suggested that a few of us meet to discuss the research and the aim of the research—at this the director agreed and said "yes, that would be very helpful." I think I will need to suggest more… not assume that we are on the same page.

1100: First interview. P02 was so candid with me- as both an NGO staff and PWA herself her information was holistic and grounded in both her own experience and her work experience as an advocate for families impacted by albinism. There was laughter when there could have been tears and yet an acknowledgement of the heaviness of this topic and the concerns around persons with albinism. The stories she shared, the personal experience of walking down the road towards home or the bus stop and the "jolts" she experiences when she hears someone behind her or something in the bushes etc. This fear that she has internalized and carries with her- what keeps her safe….this vigilance. She talked about her parents suddenly sending her and her siblings to boarding school in 2011 and them never telling her why. 2011 saw a major spike in muti-murders of PWA in Tanzania- on reflection later she realized why they sent her to boarding school: to protect her and her siblings. She talked about being thankful that her parents never told her or showed their fear/concern…this would have been distracting to her and her studies. Notes that she would not have been able to concentrate as she would have been worried about her siblings and herself (herself mentioned as an afterthought). She discussed the myth that women who have albinism are seen as a cure for illnesses/STIs/HIV- this apprehension to trust men… "Okay, why are you approaching me?" further, fear that someone will attack and rape you as a woman with albinism because of this. She notes the "jolt" occurring while she is home, while she

is walking to the bus stop esp in the dark. Notes that the human rights violations affect the psychological health of PWA- fear, constant vigilance.

Intersectional experience as both a female and as "other."

Hearing her stories as a woman, as a friend of women with children, as an Auntie, as an American, as a woman that has experienced trauma— I was teary and emotional. Lost for words. Difficult to continue the interview at one point. Recognizing that my own experience of fearing for my safety after a violation (break and entry of my home) and knowing what those "jolts" feel like for me… how exhausting they are…how distracting and yet normal they become… PERSPECTIVE shift. I can call 911 in Canada/US. I can install a security system. I can have my cell phone at my bedside, ready to go. I can drive away in my car. ETC ETC. For women here, most of these are not options. As this participant stated- even women/mothers who report to the police- most are "exonerated due to lack of evidence to connect the accused to the crime."

Also men as "in control" and as "head of the house" in Africa… mothers' hands are tied. How do they report their own spouse for abusing their child with albinism? African society as "secretive"- don't want to shame the family/expose the family.

Who is protecting women/mothers/PWA? What are the benefits of seeking protection or seeking help/justice, when this is the response? How are mothers protecting their children in ways that are not obvious? Thinking of literature re: IPV and abuse in homes—mothers creatively finding ways to keep their children safe…

Also thinking of Trauma informed practice…

Interview 03:

1545- Afternoon (I am exhausted, feeling emotional still from the 1st interview, jet lag is kicking in…I was worried about how this interview was going to go because of that)

We are in 'my' office at the NGO. I remember this time to move my chair and I sat across from participant without the desk between us. Curious if there is any dynamic in meeting in 'my' space versus their space. They set it up this way, though.

Participant sat in front of me, leaning forward enthusiastically at times. She talked with her hands a lot and mimicked how people sound when talking about albinism/asking questions/feeling suspicious etc. She acted out conversations. Very engaging and engaged. She sat with open arms, both feet on the floor, did not cross legs or arms—very open body language. Appeared quite comfortable talking about the subject even when discussing her own experiences as a PWA.

Interesting to hear her talking about "lazy mothers" versus "strong mothers"—I'm very interested in unpacking this understanding/perception further. Almost an irritation or annoyance/no time for mothers who are lazy and leave their children (abandon or leave them

with other family like grandparents)… wondering if this is a cultural interpretation that is based on behavior and actions versus theorized. Am I not understanding due to language- is her use of the English word 'lazy' actually something different with different meaning in Swahili. I should ask this question in follow up with Jane.

She expressed a great deal of pride in her upbringing- mother instilled confidence and self-esteem in her and her siblings. She knew when to be strict with them and when to be gentle/empathetic/compassionate.

Motivation for sharing: As an NGO staff and PWA who is also a mother- sense of vested interest in the topic and the research
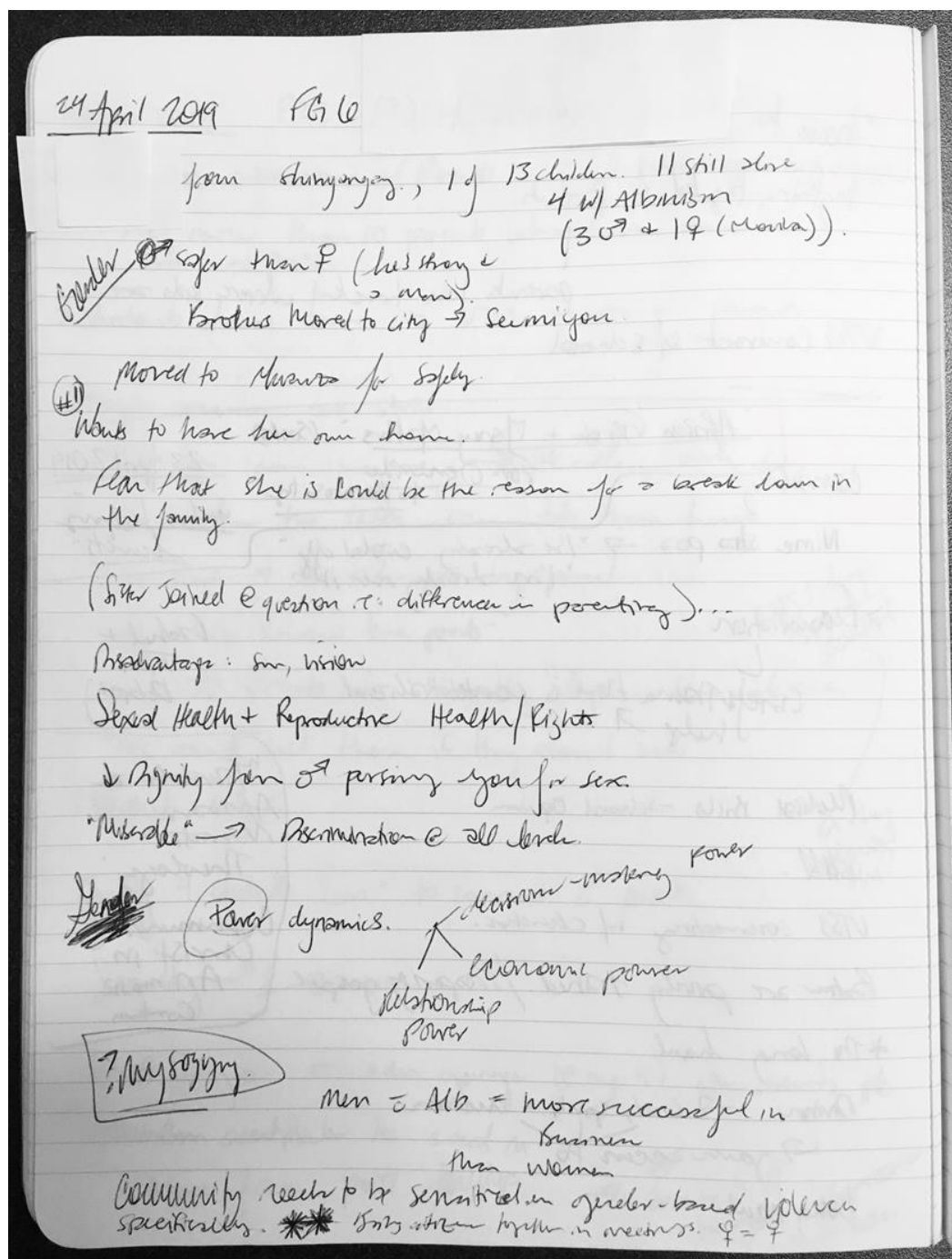
Economic status

Rape of girls and boys- particularly when they are staying with grandparents/raised by grandparents when they don't have enough attention and protection.

During this interview my jet lag really kicked in and I was struggling not to yawn. I worried that she would feel I was disinterested. At the end of the interview I did apologize and we talked about jet lag- she was very understanding and did not seem at all offended.

I recognize that this tiredness likely impacted how I asked questions/probed further etcetera

Sharing Circle fieldnotes.

24 April 2019   FG 6

from Shinyanga., 1 of 13 children. 11 still alive
                                        4 w/ Albinism
                                        (3♂ & 1♀ (Monica)).

Gender ♂ safer than ♀ (less strong
                        s arm).
          Brother Moved to city → Serumigou

① Moved to Mwanza for safety.

Wants to have her own home.

Fear that she is could be the reason for a break down in
the family.

(Sister joined @ question r: differences in parenting)...

Disadvantages: Sun, Vision

Sexual Health + Reproductive Health/Rights

↓ Dignity for ♂ pressing you for sex.

"Miserable" → Discrimination @ all levels.

Gender   (Power dynamics.   ← decision-making power
                                  Economic power
                        Relationship
                        Power

?. Mysogyny.
               Men c Alb = more successful in
                              business
                     than women

Community needs to be sensitized in gender-based violence
specifically. ✳ Boys stream higher in awareness. ♀ = ♂

Sharing Circle fieldnotes.

Individual interview fieldnotes.

Appendix J: Study Data NVIVO Codebook

Node Name	Description	Files	References
A. Vantage Point of Mothers	Standpoint; Lived Experience; Day to Day	0	0
A1. Pathways to Resistance	Ungar et al. (2007): "Examine the individuality of a [participant's] pathway to resistance" (p. 305).	5	9
A10. Accepting Motherhood & CWA		5	6
A11. Support of Other Women Impacted by Albinism		6	9
A12. Religion, Faith, Spirituality		2	2
A13. Resources (Lived Experience of)	Access to meaningful resources (quality, quantity, and accessibility). Community, NGO, Gov't. Lived experience of resources; Impact of the availability or lack of availability of resources ON DAILY LIFE.	10	32
A14. Resilience & Courage		6	18
A15. Mothers as Advocates		3	3
A16. Grief		1	1
A17. Parenting		10	21
A18. Household Income	Who is providing for the household? How are mothers earning an income/providing for their children?	2	2
A19. Stigma		2	2
Text Query for STIGMA		12	21
A2. Turning Points. Serendipity of Opportunity	Increasing resilience/capitalize on strength & resilience already present	6	8
A3. Reaching Out	Asking for help/ seeking services in the face of discrimination/ostracism	4	7
A4. Sacrifice	In the interest of her children? e.g. leaving community, work, getting creative to provide, leaving her spouse/partner	9	14
A5. Environment- DO NOT USE		3	4
A6. Separation & Reunification		7	20
A7. Burden of Worry OR Mental Health Impact on Mother		7	19

A8. Impact of Partner or Spouse Response		11	31
A9. Alone & Isolated		8	13
B. Community Responses		0	0
B1. Social Influences		0	0
B1a. SDoH		13	32
B1b. African Ontologies		15	29
B1c. Faith Communities		1	1
B1d. Media		1	1
B1e. Community & Neighbour Allyship		6	9
B1f. Broader Family Response		8	10
B1g. Community Response	Response by broader community	9	17
B1h. Gender Roles	Identified gender roles, parenting roles.	9	12
B2. Access to H&SS		0	0
B2a. Inadequate or Limited Access		12	24
B2b. Positive Interactions with H & SS		5	7
B2c. Negative Interactions OR Responses from HCPs	Responses of RNs/Midwives/Physicians to women and their children impacted by albinism	7	8
B2d. Role of NGOs or CSOs		10	22
B2e. Awareness of or Understandings of Albinism	Data re: mother's prior awareness of albinism	9	25
B2f. Perspectives of HCPs & Social Workers		3	19
B2g. Genetic Counselling		1	2
B2h. Role of Social Workers		1	2
B3. Education		0	0
B3a. Access to Education for CWA		5	10
B3b. Boarding School		7	19
B3c. Day School		3	3

B3d. Sponsored (*NGO-1*)		3	14
B3e. Positive Education Experience	Positive teacher and schooling experiences	2	2
B3f. Negative Education Experience	Negative teacher and/or schooling experience	1	1
B3g. Education Aids	vision aids, protective clothing, etc	0	0
B3h. Involvement of Mothers in Schooling	How are mothers (parents) involved or not involved in education/boarding school? Does the school or NGO attempt to keep mother and child well connected? Are mothers kept informed of child's progress/needs etc.?	3	10
D3i. Educators Perspective	data re: teachers responses/perspectives/beliefs	1	7
C. Life Stages		0	0
C1. Labour & Delivery		11	27
C2. Postpartum		9	15
C3. Preschool		5	8
C4. School Age		10	37
C5. Young Adults		4	4
C6. Siblings or How the rest of the family is impacted		7	10
D. Human Rights		0	0
D1. Women & Children (GENDER)	Article 3: the equal right of men and women to enjoy the rights in the ICESCR. Women often suffer substantial and disproportionate difficulties in securing human rights, including economic, social and cultural rights. Article 3 guarantees that men and women possess precisely the same legal entitlement to the rights set forth in the Covenant and that, if necessary, special measures will be employed by States parties to ensure that this position of equality is attained.	17	40
D10. Right to Social Security	Article 9: A large number of States do not maintain adequate social security or social insurance provisions under domestic laws protecting people in circumstances such as old age, disability, ill health or other situations not allowing them to earn a decent living. The Committee has devoted particular attention to enjoyment of the rights provided for in article	1	1

	9 by women, older persons (General Comment No. 6 (1995)),(6) and persons with disabilities (General Comment No. 5 (1994)).(7)		
D11. Right to Protection and Assistance for the Family	Article 10: provides protection for the family, mothers and children. It includes the right to enter freely into marriage... Mothers are to be accorded substantial protection before and after childbirth. The Committee on Economic, Social and Cultural Rights regularly requests information from States parties as to whether any particular groups of women lack such protection.	5	6
D12. Right to Health	Article 12: The right to the highest attainable standard of physical and mental health	10	23
D13. Right to Adequate Standard of Living	Article 11: . . . the right to housing, should not be interpreted in a narrower restrictive sense which equates it with, for example, the shelter provided by merely having a roof over one's head . . . Rather it should be seen as the right to live somewhere in security, peace and dignity . . . . (Para. 7.)	1	1
D14. Right to Education	Article 13-14: These two articles guarantee all children a right to free and compulsory primary education, wherever they may live. They also enshrine the right to equal access to education and equal enjoyment of education facilities; the freedom to choose education and to establish educational institutions; the protection of pupils against inhuman disciplinary measures; and academic freedom.	3	12
D15. Right to Protection of the Family	Article 18 of the African Charter on the Rights & Welfare of the Child: "The family shall be the natural unit and basis of society. It shall enjoy the protection and support of the State for its establishment and development.	1	5
D16. Right to Parental Care & Protection	Article 19 of the African Charter on the Rights & Welfare of the Child: "1. Every child shall be entitled to the enjoyment of parental care and protection and shall, whenever possible, have the right to reside with his or her parents. No chid shall be separated from his/her parents against his/her will...2. Every child who is separated form one or both parents shall have the right to maintain personal relations and direct contact with both parents on a regular basis."	1	5

D18. Right to Parental Responsibilities	Article20: "1. Parents or other persons responsible for the child shall have the primary responsibility for the upbringing and development of the child and shall have the duty: to ensure that the best interests of the child are their basic concern at all times...; to assist parents...and in case of need, provide material assistance and support programmes particularly with regard to nutrition, health, education, clothing, and housing.	3	8
D19. Right to Protection against Harmful Social & Cultural Practices	Article 21 of African Charter...: "State parties shall take all appropriate measures to eliminate harmful social and cultural practices affecting the welfare, dignity, normal growth and development of the child and in particular: those customs and practices prejudicial to the health or life of the child; and those customs and practices discriminator to the child on the grounds of sex or other status"	2	4
D2. Legal safeguards		7	7
D20. Separation from Parents	Article 25 of African Charter: ensures children deprived of his or her family receive alternative family care including fast placement, placement in suitable initiation for their care of children; reunite family when possible;	3	7
D21. Protection from Sale, Trafficking & Abduction	Article 29 of African Charter: State parties agree to take special measures to prevent: the abduction, sale of, or traffic in children for any purpose by any person including family	1	2
D3. HR as International Covenant		1	1
D4. Violence or Threats of Violence		11	19
D5. Access to Justice		7	10
D6. Family Involvement in HR Violation	Parent, Family member involved in carrying out act of violence or threat against CWA for financial gain	4	5
D7. Right to Non-Discrimination	Article 2: The States Parties to the present Covenant undertake to guarantee that the rights enunciated in the present Covenant will be exercised without discrimination of any kind as to race, colour, sex, language, religion, political or other opinion, national or social origin property, birth or other status.	6	9

D8. Right to Self Determination (AGENCY)	Article 1: All peoples have the right of self-determination. By virtue of that right they freely determine their political status and freely pursue their economic, social and cultural development.	3	5
D9. Right to Work	Article 6-7: The States Parties to the present Covenant recognize the right to work, which includes the right of everyone to the opportunity to gain his living by work which he freely chooses or accepts, and will take appropriate steps to safeguard this right. the right of everyone to the enjoyment of just and favourable conditions of work	3	4
E. Identified Needs by Mothers		0	0
E1. Household support		8	14
E2. Capital & Income		5	6
E3. Groups		5	7
E4. Spread Understanding Albinism Education	education for HCP, SS, lay people	3	3
E5. Sponsorship		2	3
E6. Quality Education for Children		2	2
F. Ideas Identified by CL or Partners		0	0
F1. Financial Empowerment		5	5
F2. Holistic Family Support		5	11
F3. Disparities between MWA and Mothers of CWA	Identifying how the experiences differ for mothers with albinism versus for mothers who have children with albinism	1	1
F4. Albinism Education for the Whole Family	Ensuring opportunities for entire families (including extended family) to receive education re: albinism. Education that isn't just from the mother.	3	3
F5. Attune to Intersectionality	How do organizations ensure that their responses are attune to the intersectional concerns of women	2	6
F6. Maslow's Hierarchy of Needs		3	9
F7. All Org's Recognizing their Unique Role	NGOs/CSOs/Gov't Orgs recognizing their role in responding to the needs of women and girls regardless of 'category' (i.e., not passing her off to the next organization who deals	1	1

	with albinism simply because she has albinism)		
F8. SDG's		0	0
F9. Perspectives of NGO Staff re mothering		2	3
G. Research Methodology		0	0
G1. Interpreter & Cultural Liaison		6	14
G2. Recruitment & Participants		1	1
G3. Setting		1	2
G4. Researcher Reflections		2	7
H. Question Marks	Data that is telling us something, but we don't know what yet	1	1
I. Group Coding		4	7
J. P25- Under the Tree		1	1
J1. Mothers with Albinism		3	5
K. Poignant & Important Quotes for Writing		7	11

Appendix K: Trinity Western University REB Certificates of Approval

TRINITY WESTERN UNIVERSITY

Human Research Ethics Board - Trinity Western University
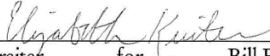
Certificate of Approval

Principal Investigator: Emma Strobell

Department: Nursing

Supervisor (if student research): Sheryl Reimer-Kirkham

Co-Investigators:

> **Title:** Exploring the mothering experience of women who have children with albinism in Tanzania

HREB File No.: 18G08

Approval Date: July 5, 2018

Certificate Expiry Date: July 4, 2019

Certification

This is to certify that Trinity Western University Human Research Ethics Board (HREB) has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans.

Elizabeth Kreiter   for   Bill Badke
M.L.I.S.   M.Th., M.L.S.
HREB Coordinator   HREB Chair

This Certificate of Approval is valid for one year and may be renewed.
The HREB must be notified of *all* changes in protocol, procedures, or consent forms.
A final project form must be submitted upon completion.
The required forms for the above are at:
https://www.twu.ca/research/research-services/research-ethics/approval-forms

7600 Glover Rd., Langley, BC, Canada, V2Y 1Y1 T: (604) 888-7511, F: (604) 513-2047

TRINITY WESTERN UNIVERSITY

Human Research Ethics Board - Trinity Western University

Certificate of Approval – Renewal

Principal Investigator: Emma Strobell

Department: Nursing

Supervisor (if student research): Sheryl Reimer-Kirkham

Co-Investigators:

> **Title:** Exploring the mothering experience of women who have children with albinism in Tanzania

HREB File No.: 18G08

Approval Date: July 17, 2019

Certificate Expiry Date: July 16, 2020

Certification

This is to certify that Trinity Western University Human Research Ethics Board (HREB) has examined the research proposal and concludes that, in all respects, the proposed research meets appropriate standards of ethics as outlined by the Tri-Council Policy Statement: Ethical Conduct of Research Involving Humans.

Elizabeth Kreiter   for   Bill Badke
M.L.I.S.   M.Th., M.L.S.
HREB Coordinator   HREB Chair

This Certificate of Approval is valid until the expiry date and may be renewed.
The HREB must be notified of *all* changes in protocol, procedures, or consent forms.
A final project form must be submitted upon completion.
The required forms for the above are at:
https://www.twu.ca/research/research-services/research-ethics/approval-forms

7600 Glover Rd., Langley, BC, Canada, V2Y 1Y1 | T: 604-513-2167

Appendix L: COSTECH Research Permit

UNITED REPUBLIC OF TANZANIA

TANZANIA COMMISSION FOR SCIENCE AND TECHNOLOGY (COSTECH)

RESEARCH PERMIT

Permit No.	2018–448- NA-2018- 296
Date	4th December 2018
Researcher's Name	Emma Strobell
Nationality	Canadian
Research Title	Mothering and Albinism in Tanzania
Research Area(s)/Region(s)	Manyara, Dar es Salaam
Validity	From: 4th December 2018 to 3rd December 2019
Local contact/collaborator (with affiliated institution)	Dr. Nandera Mhando, University of Dar es Salaam, P.O. Box 35043, Dar es Salaam

-----------------------------   ------------------------------
PROGRAMM OFFICER   **for: DIRECTOR GENERAL**

IMPORTANT REQUIREMENTS

- Research permit that involve collecting human, plant or animal materials / data that will be exported outside Tanzania must submit a signed Material Transfer Agreement (MTA), Data Transfer Agreement (DTA) between Tanzania host institution and the foreign counterpart. The MTA/DTA will indicate terms for collecting, storing/managing, transporting, disposal or returning of the materials/DATA to Tanzania after the closure of the research project.
- Any patent or intellectual property and royalty emanating from any research approved by the National Research Registration Committee (NRRC) shall be owned as stipulated in the research proposals and in accordance with the IP policy of the respective research institutions.
- All researchers are required to report to a Regional Administrative Secretary (RAS) of the study area and present the introduction letter and activity schedule(plan) prior starting any research activity.
- All researchers are required to submit quarterly progress reports and all relevant publications made after completion of the research.
- All communications should be addressed to COSTECH Director General through rclearance@costech.or.tz; dg@costech.or.tz or +255222700749; +255 (022) 2771358. Terms and conditions of the permit are found at www.costech.or.tz

Appendix M: NIMR Ethical Clearance Certificate

THE UNITED REPUBLIC OF TANZANIA

National Institute for Medical Research
3 Barack Obama Drive
P.O. Box 9653
11101 Dar es Salaam
Tel: 255 22 2121400
Fax: 255 22 2121360
E-mail: ethics@nimr.or.tz

Ministry of Health, Community
Development, Gender, Elderly & Children
University of Dodoma, College of
Business Studies and Law
Building No. 11
P.O. Box 743
40478 Dodoma

NIMR/HQ/R.8a/Vol. IX/2956

16th November, 2018

Emma Strobell
Trinity Western University
School of Nursing
Dr. Nandera Ernest Mhando
University of Dar es Salam
P.O. Box 35043
Dar es Salaam

RE: ETHICAL CLEARANCE CERTIFICATE FOR CONDUCTING MEDICAL RESEARCH IN TANZANIA

This is to certify that the research entitled: Mothering and albinism in Tanzania (Strobell E. et al), has been granted ethical clearance to be conducted in Tanzania.

The Principal Investigator of the study must ensure that the following conditions are fulfilled:

1. Progress report is submitted to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research, Regional and District Medical Officers after every six months.
2. Permission to publish the results is obtained from National Institute for Medical Research.
3. Copies of final publications are made available to the Ministry of Health, Community Development, Gender, Elderly & Children and the National Institute for Medical Research.
4. Any researcher, who contravenes or fails to comply with these conditions, shall be guilty of an offence and shall be liable on conviction to a fine as per NIMR Act No. 23 of 1979, PART III Section 10(2).
5. Sites: Mwanza, Dar es Salaam region.

Approval is valid for one year: 16th November 2018 to 15th November 2019.

Name: Prof. Yunus Daud Mgaya

Name: Prof. Muhammad Bakari Kambi

Signature
CHAIRPERSON
MEDICAL RESEARCH
COORDINATING COMMITTEE

Signature
CHIEF MEDICAL OFFICER
MINISTRY OF HEALTH, COMMUNITY
DEVELOPMENT, GENDER, ELDERLY &
CHILDREN

CC: Director, Health Services-TAMISEMI, Dodoma
     RMO of Mwanza, Dar es Salaam region
     DMO/DED of respective districts

Appendix N: Consent Form for Mothers

INSPIRING HEARTS & MINDS

TRINITY WESTERN UNIVERSITY | SCHOOL OF NURSING

Mothering and Albinism in Tanzania

Mothers and Caregivers Consent Form

Emma Strobell RN, BScN
Principal Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

Sheryl Reimer-Kirkham RN, PhD
Supervisor and Professor
Trinity Western University School of Nursing
604 513 2121 ext. 3239| sheryl.kirkham@twu.ca

This research is part of a Thesis submitted in partial fulfilment of the requirements for the degree of Masters of Science in Nursing at Trinity Western University.

Who am I? My name is Emma Strobell and I am a student from Trinity Western University in Canada. I am studying in the nursing department.

What am I asking of you? You are being asked to take part in a study that I am working on. The project is about what it is like to be a mother or caregiver of a child with albinism. You can read this form or we can talk about it and I can spend a few minutes telling you about the project. I will then ask you if you want to take part in the project.

This study is in partnership with   . You need to be at least 18 years old to join the study.

If you decide to take part in this study, you will be asked questions about what it is like for you to be a mother or caregiver of a child with albinism.

This will take about an hour, either on your own or in a group with other women who have children with albinism. If you would like to talk to me again after this interview, we could do so either at an program or we could set up another meeting.

During the interview if you do not want to answer a question or you don't know the answer to a question, you can tell me that you do not want to answer or that 'I do not know.' I will audio-record the interview and then it will be typed out. I will assign your name a code so that your actual name is not on anything. Our conversation will be in a location that you agree to. I will pay for your transportation to and from the interview or group meeting at the   office and will provide refreshments.

The only known risk involved in being in this study is that talking about some of your experiences, memories, or fears might be emotional for you . There will be an   worker who will be able to talk to you if you want them to. Also, if you feel at any time it is too hard to continue or you do not want to continue, we can stop the interview. Nothing bad will happen if you do not continue with the study,   and I will treat you the same no matter what.

The information that I learn in this study might help you and other women with similar stories. This study might also help make sure that you have the resources that you feel you need and that your (both your child's and your own) human rights are protected.

The things you say and any information I write about you will not have your name with it, so no one will know they are your answers or the things that you talked about. I will keep the recorded interview and all paperwork in a locked bag with me at all times while I am travelling. I will keep it in a locked filing cabinet in Canada. I will use strict security measures on my computer and any devices I use to store the information you share with me to keep it safe. I will keep all of the study information for 5 years so that I can use it in other studies or to help publish related results. After 5 years, all of the study materials will be destroyed.

I will not let anyone other than my supervisors see your answers or any other information about you.

You do not have to be in the study. No one will get angry or upset with you if you do not want to do this. Just tell me if you do not want to be in the study. And, if you decide to be in the study now but later you change your mind, then you can tell me you do not want to be in the study anymore. You will not have to return the money if you choose to withdraw from the study at any point. If you decide not to be part of the study anymore, your information and anything you shared with me will be deleted and papers will be destroyed.

You can ask me questions at any time. You can ask now or you can as me later in the study. If you want to talk to someone about your rights or how you are treated during this study, you can talk to Elizabeth Kreiter in the Office of Research, Trinity Western University. You can call her at 604-513-2167 or email her at researchethicsboard@twu.ca. You can also talk to the researcher's supervisors, Dr. Sheryl Reimer-Kirkham or Dr. Barb Astle, Trinity Western University, School of Nursing, by emailing them at sheryl.kirkham@twu.ca or barbara.astle@twu.ca or by telephone at 604 513 2121 ext. 3239 or ext. 3260.

You may contact me at any time by calling me at (604) 353-0099 or by emailing me at emma.strobell@mytwu.ca.

If you want to be in the study, sign your name on the line below. I will give you a copy of this form to take home.

_____   _____
Signature of Participant   Date

_____   _____
Signature of Principal Investigator   Date

_____   _____
Signature of Interpreter (if required)   Date

TRINITY WESTERN UNIVERSITY | **SCHOOL OF NURSING**

Kuchunguza maisha yay a ulezi ya kina mama wenye watoto wenye ualbino

<u>**Fomu ya ridhaa kwa kina mama na walezi**</u>

Emma Strobell RN, BScN
Mchunguzi mkuu
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

Sheryl Reimer-Kirkham RN, PhD
Msimamizi na Profesa
Trinity Western University School of Nursing
604.513-2121 ext 3239 | sheryl.kirkham@twu.ca

Mimi ni nani? Kwa jina mimi ni Emma Strobell mwanafunzi katika chuo kikuu cha Trinity Western kanada, kitivo cha nesi.
Je nahitaji nini kutoka kwako? Watarajiwa kushiriki katika utafiti huu ambao lengo lake ni kubaini mengi kuhusu kina mama au walezi wa watoto wenye ualbino. Waweza jisomea mradi huu au twaweza kuujadili kwa dakika chache kisha nitakuuliza maswali iwapo utahiari kushiriki.
Utafi   azima we umetimu umri wa miaka 18 kushiriki.
Iwapo utahiari kushiriki utaulizwa maswali ya je I vipi kuwa mama au mlezi wa mtoto Mwenye ualbino
Hili litachukua muda wa saa moja aidha pekee yako au katika kikundi cha kina mama au walezi wa watoto wenye ualbino. Iwapo ungependa kikao cha faragha name baadaye, basi tutafanya hivyo chini ya mpango   TSS au tutapanga kikao kingine nawe.

Kwenye mahojiano, iwapo hautaki au haujui jibu lolote kuhusiana na swali u hiari kusema haujuui au haupo tayari kulijibu. Mahojiano haya yataweza kurekodiwa na baadaye kunukuliwa. Nitakupa jina la msimbo, hivi kwamba hautatumia jina lako. Mkutano wetu utakuwa katika kikao utakachopendekeza na nitagharamia uchukuzi wako wa kuja na kurudi katika mahojiano au katika ofis ΓSS kwa mahojiano ya kikundi ambapo tutakuwa na viburudishi.

Maneno utakayoyasema na ujumbe wowote nitakaounakili kukuhusu hautakuwa na jina lako, kwa hivyo hakuna atakayefahamu kuwa majibu yale yametoka kwako. Mahojiano yetu yote nitayaweka kwa usiri nitakapokuwa nikisafiri na pia kwenye sefu kule Kanada. Nitaweweka mikakati dhabiti ya usalama katika tarakilishi na vifaa vingine vyote nitakavyotumia katika mahojiano yetu. Nitayaweka mahojiano haya na jumbe zingine zozote kwa muda wa miaka tano ijayo kwa minajili ya utafiti mwingine wa kimasomo na baadaye nitaweza kuziharibu.

Sitaweza kumwacha mtu mwingine kuyaona majibu yako ila msimamizi wangu.

Sio lazima ushiriki katika utafiti huu. Hakuna atakayekasirika au kuudhika utakapohiari kutoka katikka utafiti huu. U hiari kusema hauko tayari kushiriiki. Iwapo umejisajili kwenye utafiti huu kisha usikie kwamba haujihisi kushiriki,u hiari kusema. Hautalazimika kurudisha pesa zozote ulizopewa. Na ujumbe wowote utakaokuwa umepeana kufikia hapo utaweza kufutwa katika nakala na kuharibiwa.

Iwapo una swali lolote waweza kuuliza mahojiano yakiendelea au baada ya mahojiano. Iwapo ungependa kuongea kuhusu haki zako na jinsi ulivyohudumiwa kipindi cha utafiti huu u hiari kuwajuza wafuatao; Elizabeth Kreiler, ofisi za utafiti chuo kikuu cha Trinity Western Kanada au umpigie kupitia 604-513-2167 au kwenye barua pepe; researchethicsboard@twu.ca . pia waweza kuwasiliana na msimamizi wangu , Dr. Sheryl Kirkmau au Dr. Barb Astle Chuo kikuu cha Trinity Western Canada kitivo cha unesi,kwenye namba za

rununu zifuatazo; 604-513-2121,ext 3239, au ext. 3260 a kwenye baruapepe zao Sheryl.kirkman@twu.ca au barb.castle@twu.ca. Mimi waweza kunipata wakati wowote kupitia 604-353-0099 au kupitia barua pepe; emma.strobell@mytwu.ca.

Iwapo ungependa kushiriki kwenye huu utafiti basi tia sahihi kwenye laini iliyopo hapo chini na nitakupa nakala yako ya hii fomu kwenda nayo nyumbani.

_____

Sahihi ya mshiriki   tarehe

_____

Sahihi ya mchunguzi mkuu   tarehe

_____

Sahihi ya mkalimani   tarehe
(iwapo atahitajika)

Appendix O: Consent Form for Key Informants

INSPIRING HEARTS & MINDS

TRINITY WESTERN UNIVERSITY | SCHOOL OF NURSING

Mothering and Albinism in Tanzania

Key Informant Consent Form

Emma Strobell RN, BScN
Principal Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

Sheryl Reimer-Kirkham RN, PhD
Supervisor and Professor
Trinity Western University School of Nursing
604.513-2121 ext 3239 | sheryl.kirkham@twu.ca

This research is part of a Thesis submitted in partial fulfilment of the requirements for the degree of Masters of Science in Nursing at Trinity Western University.

You are being asked to participate in a research study that is in partnership with

Purpose: The purpose of this research study is to explore the lived experiences of mothers or primary caretakers of children with albinism. You are asked to be interviewed to share your knowledge as a key informant (activist/advocate/researcher/person with albinism). You understand that you must be at least 18 years old to participate in this study.

Procedures: If you agree to participate in this study, you will be interviewed for approximately 60 minutes by the Principal Investigator. The interview will be audio-recorded and take place in a location agreed upon by you and the Principal Investigator.

No identifying information will be included when the interview is transcribed. You understand that you will not receive any compensation for your participation in this study. A summary of the research findings will be made available to the participants by the Principal Investigator.

Potential Risks: There are no known risks for key stakeholders associated with this study. If you feel at any point you need to withdraw from the study, please know that you can do so with no negative consequences.

Potential Benefits to Participants or to Society: You realize that the knowledge gained from this study may help expose current gaps in resources and protection that mothers and their children with albinism experience while also exploring both their perspectives as well as your key insights as to potential solutions. This study may also help in the effort to promote the enjoyment of human rights of persons with albinism.

Confidentiality: You understand that all of the study data (recorded interviews/focus groups, transcripts, and fieldnotes) will be kept confidential and in a secure location with password and encryption protection. You will be given a participant number and your name will not be used in any reports. When transporting de-identified data between physical locations, data will be stored in a locked briefcase and remain with the Principal Investigator. The data will be used in publications and presentations (but will not include any identifying information about you). The study data will be kept for 5 years in a

secure, locked filing cabinet for potential use in future studies or publications with the approval of an REB.

Contacts: If you have any concerns about your treatment or rights as a research participant, you may contact Elizabeth Kreiter in the Office of Research, Trinity Western University at 604-513-2167 or researchethicsboard@twu.ca.

If you need to, you may contact the researcher's supervisors, Dr. Sheryl Reimer-Kirkham or Dr. Barbara Astle, Trinity Western University, School of Nursing, at any time via email at Sheryl.kirkham@twu.ca or barbara.astle@twu.ca or by telephone at 604 513 2121 ext. 3239 or ext. 3260, respectively.

At any point during or after the study, you are welcome to contact the Principal Investigator, Emma Strobell, via email at emma.strobell@mytwu.ca or by telephone at 1(604) 353-0099.

Consent: You understand that your participation in this study is completely voluntary and that, at any time, you may withdraw from the study if you want to—there will be absolutely no negative response from the researcher or   should you choose to withdraw from the study. To withdraw from the study, please contact the Principal
Investigator directly via email or by telephone. You may withdraw at any time until the final submission for internal defense occurs at the university in Spring 2019. If you withdraw from the study, your information and data supplied will be deleted from devices and papers will be shredded.

By signing this document, you are acknowledging that this study has been explained to you. You have read and understand this consent form, all of your questions have been answered, and you agree to participate. You will receive a copy of this consent form to take home.

_____   _____
Signature of Participant   Date

_____   _____
Signature of Principal Investigator   Date

_____   _____
Signature of Interpreter (if required)   Date

INSPIRING HEARTS & MINDS

TRINITY WESTERN UNIVERSITY | SCHOOL OF NURSING

Kuchunguza maisha ya ulezi ya kina mama wenye watoto wenye ualbino

 Fomu ya ridhaa kwa watoa taarifa maalum

Emma Strobell RN, BScN
Mchunguzi mkuu
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

Sheryl Reimer-Kirkham RN, PhD
Msimamizi na Profesa
Trinity Western University School of Nursing
604.513-2121 ext 3239 | sheryl.kirkham@twu.ca

Waulizwa kushiriki kwenye utafiti huu wenye ushirikiano na

Madhumuni; madhuumuni au lengo la utafiti huu ni kujua maisha wanayoyapitia kina mama au walezi wa watoto wenye ualbino. Unaombwa kushiriki kwenye mahojiano kama mshiriki (mwanaharakati,wakili, mtafiti au mtu Mwenye ualbino.) elewa fika kwamba lazima uwe umetimu umri wa miaka 18 kushiriki kwenye huu utafiti.

Utaratibu; utakapokubali mahojiano haya, utaweza kuwa na kikao na mchunguzi mkuu kwa muda wa saa moja ambapo mahojiano yataweza kunakiliwa na kurekodiwa na yatakuwa katika kikao mtakachoafikiana na mchunguzi mkuu. Hakuna ujumbe utakao kuashiria mahaojiana yatakapokuwa yakinukuliwa. Elewa fika kuwa

hautapata fidia yoyote kwa ajili ya kushiriki utafiti huu. Muhtasari wa matokeo ya mahojiano haya utapewa mshiriki kupitia kwa mchunguzi mkuu.

Hatari mwandamazo; hakuna harari fika zinazojulikana kwa washikadau wowote watakaoshiriki kwenye mahojiano haya. Iwapo utajihisi kwa wakati wowote kuondoka kwenye utafiti huu, juu u hiari kutoka na bila matokeo mabaya.

Faida kwa watakaoshiriki utafiti; utaelewa kuwa ujuzi utakaopata katika utafiti huu utaweza kuleta bayana mapengo yaliyopo katika rasilimali na ulinzi ambao kina mama na watoto wenye ualbino wanayapitia na pia mitazamo yao na njia waweza suluhisha baadhi ya shida hizo. Utafiti huu utaweza pia kuwafaidi wenye ualbino kufurahia haki zao za kibinadamu.

Siri; elewa fika kwamba ujumbe wowote utakaonakiliwa kwenye mahojiano, au mahojiano ya vikundi yatawekwa kwenye usiri na pahali salama na kudhibitiwa na nywila na usimbaji fiche. Tapewa namba ya ushiriki, hivyo jina lako halitatumika kwenye ripoti. Katika usafirishaji wa jumbe takiwa kutoka eneo moja mpaka jingine, deta itawekwa kwenye mkoba salama na kuachwa na mchunguzi mkuu. Ujumbe huu utaweza kutumiwa kwenye uchapishaji na uwasilisho (lakini jina lako halitatumika popote). Jumbe za utafiti huu zitawekwa kwa muda wa miaka 5 pahali salama na zawezakutumiwa katika tafiti za baadaye au chapisho lakini chini ya idhinisho la REB

Wasiliana; Iwapo ungependa kuongea kuhusu haki zako na jinsi ulivyohudumiwa kipindi cha utafiti huu u hiari kuwajuza wafuatao; Elizabeth Kreiler, ofisi za utafiti chuo kikuu cha Trinity Western Kanada au umpigie kupitia 604-513-2167 au kwenye barua pepe; researchethicsboard@twu.ca . pia waweza kuwasiliana na msimamizi wangu , Dr. Sheryl Kirkmau au Dr. Barbara Astle Chuo kikuu cha Trinity Western Canada kitivo cha unesi,kwenye namba za rununu zifuatazo; 604-513-2121,ext 3239, au ext. 3260 mtawalia au kwenye baruapepe zao Sheryl.kirkham@twu.ca au barbara.astle@twu.ca.

Pia waweza kumfikia mchunguzi mkuu Emma Strobell wakati au baada ya utafiti kwa; 604-353-0099 au kupitia barua pepe; emma.strobell@mytwu.ca.

Ridhaa; unaelewa fika kuwa ushiriki wako katika utafiti huu ni kwa kujitolea na u hiari kutoka wakati wowote utakapo.- hakutakuwepo na jawabu lolote hasi kutoka kwa mtafiti au   uamuapo kutoka. Kujiondoa kwenye utafiti, mweleze mtafiti/mchunguzi mkuu moja kwa moja kupitia nambari yake ya simu au barua pepe .

Waweza jiondoa wakati wowote kwenye utafiti huu mpaka wakati wa wasilisho la mwisho la usajili wa tasnifu wa utafiti katika chuo kikuu kipindi cha Demani 2019. Utakapojiondoa kwenye utafiti huu, jina lako na ujumbe wowote wako utafutwa kwenye vifaa vyote na karatasi kuchanwa.

Kwa kutia sahihi fomu hii, wathibitsha kuwa tafiti huu ulieleiezwa kwako, umesoma na kuelewa fomu ya ridhaa, maswali yako yamejibiw na umekubali kushiriki. Utapata nakala yako ya hii fomu kwenda nayo nyumbani.

_____   _____

Sahihi ya mshiriki   tarehe

_____   _____

Sahihi ya mchunguzi mkuu   tarehe

_____   _____

Sahihi ya mkalimani   tarehe

(iwapo atahitajika)

Appendix P: Debrief Form for Mothers

INSPIRING HEARTS & MINDS

TRINITY WESTERN UNIVERSITY | SCHOOL OF NURSING

*Exploring the Mothering Experience of Women Who Have Children
with Albinism*

Mothers and Caregivers Debriefing Form

Emma Strobell RN, BScN
Principle Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

Thank you for your participation in this study. Your willingness to share your experience as a mother or caregiver with a child who has albinism is so appreciated. Your story and ideas alongside those of other mothers and caregivers like you will help others to learn about your experience from your perspective as well as how best to respond.

If you have experienced distress as a result of talking about your experiences, you may want to talk with a trusted friend, relative, or other close person in your life. If you are already connected with the staff at this NGO, they know about this study and are able to talk with you. If you need help getting in touch with them, I can give you contact information.

Even though we have finished the interview/group discussion, if you want to withdraw your participation in this study, you may do so by telling me at any time (until final submission of the completed study- anticipated in 2020). If you are unable to call or email me directly, TSS staff will help you contact me by email. Nothing bad will happen if you choose to withdraw your participation- you will be treated the same by me and TSS staff.

If you have any questions or concerns, please contact me by email at emma.strobell@mytwu.ca or by telephone at 604-353-0099. If you would like to speak with my supervisors, Dr. Sheryl Reimer-Kirkham

and Dr. Barb Astle, please email either one of them at
Sheryl.kirkham@twu.ca or barb.astle@twu.ca.

If you would like a copy of the final study, please tick this box. ☐

Appendix Q: Debrief Form for Key Informants

Approved: July 5, 2018

INSPIRING HEARTS & MINDS

TRINITY WESTERN UNIVERSITY | SCHOOL OF NURSING

Exploring the Mothering Experience of Women Who Have Children with Albinism

Key Informant Debriefing Form

Emma Strobell RN, BScN
Principle Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC
604 353 0099 | emma.strobell@mytwu.ca

Thank you for your participation in this study. Your willingness to share your experience and knowledge as a key informant within this area is greatly appreciated. The knowledge and recommendations you have provided, alongside that of mothers with children who have albinism, will contribute to the literature available on this specific population that is greatly impacted by social and contextual factors associated with albinism within sub-Saharan Africa.

If you have experienced distress as a result of talking about your experiences working alongside this population, you may want to talk with a trusted friend, relative, colleague, or other close person in your life.

Even though we have finished the interview, if you want to withdraw your participation in this study, you may do so by contacting me at any time (until final submission for internal defense- anticipated in 2020). There will be no negative impact if you choose to withdraw your participation.

If you have any questions or concerns, please contact the PI by email at emma.strobell@mytwu.ca or by telephone at 604-353-0099. If you would like to speak with the PI's supervisors, Dr. Sheryl Reimer-Kirkham and Dr. Barb Astle, please email either one of them at sheryl.kirkham@twu.ca or barb.astle@twu.ca.

If you would like a copy of the final study, please tick this box. ☐