



Birth stories of South African mothers of children with albinism: A critical human rights analysis

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ABSTRACT

Background: The genetic condition of oculocutaneous albinism is disproportionately present in Africa. Little research has addressed the experiences of mothers impacted by albinism, even though they are more likely to be impacted by human rights violations.

Methods: A qualitative study was designed to examine the resilience of mothers affected by albinism in South Africa. Virtual and in-person fieldwork was conducted with the facilitation of community-based researchers and local cultural liaisons.

Findings: Giving birth to a child with albinism in South Africa, as in many parts of sub-Saharan Africa, was a life-defining moment for mothers and their families, setting them on a trajectory of health-related stigma, gender inequalities, reduced access to social determinants of health, and other human rights violations. Mothers engaged in sense-making processes shaped by the responses of birth attendants and families, and that reflected social discourses. Their resilience was impacted by access to health teaching, genetic counselling, and health and social services, which were often incomplete or absent all together. Civil society organizations, peer groups, and faith communities were vital in filling these gaps.

Conclusions: The experience giving birth to a child with albinism was both the same and different compared to mothers forty years earlier. What varied was the digital availability of health information; progressive health and social policies and resourcing; and human rights instruments. These transformations point to best practices to support mothers' resilience.

1. Introduction

Oculocutaneous albinism is disproportionately prevalent in Africa (Chu et al., 2021), yet it is an under researched area. A human rights movement, with the United Nations (UN) appointment in 2015 of an Independent Expert on the enjoyment of human rights by persons with albinism, has emerged in response to recent violence against persons with albinism (PWA). In this paper, we present the findings of a qualitative study exploring the resilience of mothers in South Africa impacted

by albinism. We do so through a human rights lens, focusing on the perinatal period and building on the earlier ground-breaking work of Dr. Jennifer Kromberg.

2. Background and literature review

2.1. South African context

South Africa is a middle-income country with an increasing

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population of approximately 60.6 million people, of which 49.1 million are Black Africans, 5.3 million are of mixed ancestry, 4.3 million are Caucasoid, and 1.6 million are of Indian/Asian origin (Statistics South Africa, 2022). The healthcare system has undergone significant improvements over the last decades, as it transitions to universal healthcare access, national health insurance, and primary health care (Ojo, 2018; Rispel et al., 2019). Maternal and infant mortality rates have decreased steadily, showing the effectiveness of policy directions and healthcare interventions (Moodley et al., 2020). Even with such improvements, the health care system is plagued with structural issues, health care inequalities, and poor health outcomes, as the country is burdened with diseases such as HIV/AIDs and tuberculosis (Ojo, 2018; Rispel et al., 2019; WHO, 2016). Approximately 71.9 % of the population (most of whom are black African) uses publicly funded services which face lower human-resourcing ratios, financial constraints, and ageing infrastructure (Ranchod et al., 2017; Rispel, 2016), while approximately 27 % of the population (most of whom are Caucasian, 88 %) use private healthcare services (Statistics South Africa, 2021) which are well resourced.

2.2. Albinism and maternal health

Albinism has been observed, described, and commented upon for many centuries in Africa (Kromberg & Kerr, 2022). There are several types, but the commonest is oculocutaneous albinism (OCA), which is recessively inherited and associated with a lack of pigment in the eyes, skin, and hair (Montoliu et al., 2014). The prevalence rate of OCA is estimated to be between 1 in 1800 and 1 in 5000 in sub-Saharan Africa (Lund & Roberts, 2018). In South Africa, the prevalence is estimated to be 1 in 3,900 (Kromberg et al., 2023).

Research on the psychosocial dimensions of albinism in South Africa began with Dr. Jennifer Kromberg's research in the 1970s on youth with albinism (Kromberg, 1977). She then investigated prospectively over 15 months the way in which black mothers responded to their newborn infants with albinism and found a delay in maternal attachment and bonding (Kromberg, 1985). Mothers believed the common myths associated with the condition, i.e., that PWA are not real people, but are spirits, less than human, and do not die of a natural death (Imafidon, 2020; Kromberg, 1992). Due to these beliefs, mothers often feared that they had given birth to something unnatural, and this feeling led to confusion, making it difficult to establish maternal-infant bonding. Kromberg's (1985) research also showed that mothers' birthing experiences were influenced by the reactions from the healthcare providers, who often displayed initial shock with vague or lack of patient education. Family and community members similarly had an impact on the mothers' experiences, with accusations and mockery stemming from misunderstandings about albinism. These beliefs (which continue) often related to the poorly understood causes of albinism as: a curse; a punishment for bad deeds from ancestral spirits or demons; contagious; or due to sleeping with a white man (Baker et al., 2010; Kromberg, 1985; Reimer-Kirkham et al., 2019; Taylor et al., 2021).

In the intervening years since Kromberg's research, minimal research has focused on mothering and albinism. Now, decades later, research conducted in Tanzania (Reimer-Kirkham et al., 2020; Strobell, 2020), Uganda (Taylor et al., 2021), and Malawi (Likumbo et al., 2021) has found similar experiences, marked by varied responses from healthcare providers (many reinforcing the fear and shock of seeing a child born with albinism, others showing support). In these studies, mothers rarely receive education about albinism prior to leaving the birthing facility. Myths and misunderstandings about the condition persist, leading to continued uncertainty and fear for the safety and well-being of their children. This research has also shown the effectiveness of counteracting negative beliefs, empowering the mothers, and giving them information on the genetic cause of albinism and how best to manage it (Baker et al., 2010; Kromberg & Manga, 2018; Strobell, 2020; Taylor et al., 2021). Non-government organizations (NGOs) offer

services such as education about albinism, sponsorship for education, and access to skin and vision care (Reimer-Kirkham et al., 2021; Strobell, 2020). NGO-sponsored support groups were highlighted as providing psychosocial support and opportunities for income generation, which in turn enabled mothers to advocate as human rights defenders for the health and well-being of their children (Ero et al., in press; Ibhawoh et al., 2022; Reimer-Kirkham et al., 2020; & Strobell, 2020).

3. Methods

3.1. Study purpose

The purpose of the project was to explore through a human rights lens the resilience of mothers affected by albinism, at the intersection of gender, colourism, and religion (Funding: Social Sciences and Humanities Research Council Canada). We designed a 3-country (Tanzania, South Africa, and Ghana) qualitative study, with the objectives to:

1. examine the everyday lives of mothers affected by albinism in relation to resilience, security and well-being, and parenting and provision for their families;
2. describe how mothers and their children impacted by albinism access community services, such as social and health services, education, and employment;
3. explore social constructions of gender and colourism in relation to albinism in the contexts of Tanzania, South Africa, and Ghana, and their impact on the experience of mothering;
4. analyse how the spiritual/cultural beliefs and practices, and the threat of witchcraft-related harmful practices, impact on the experience of mothering and albinism; and.
5. articulate recommendations for the protection and promotion of the human rights of these mothers and their children.

In this paper, we focus on the South African phase. Qualitative inquiry, informed by critical perspectives, was employed as a method for the study of culture, paying particular attention to power relations, including the researchers' position vis-à-vis the field of study (Newnham et al., 2021). As a sub-group of an international research-policy-advocacy network with funding from Social Sciences and Humanities Research Council Canada, the authors hold various social locations, some as white settler Canadians, and most from South Africa (of Black African ancestry or Caucasian ancestry). Four (and two cultural liaisons) are PWA or mothers of children with albinism.

3.2. Data collection

Recruitment was facilitated by community-based researchers (Mazibuko, Tjope, and Mgiijima-Konopi) and cultural liaisons, with convenience and purposive sampling, with a final sample of 36 participants: 22 mothers impacted by albinism and 14 key stakeholders engaged with families impacted by albinism (genetic counsellors, dermatologist, civil society staff, policy makers, faith leader, and traditional healers) (See Table 1). Interview guides had questions tailored to participants (e.g., stakeholders' questions differed somewhat from mothers' questions while both addressing the phenomenon under investigation). Because of COVID-19 safety precautions, most data collection involved individual interviews rather than listening circles as we had conducted in Tanzania. Interviews, lasting 30 – 90 min, were audio recorded, transcribed, and uploaded to NVivo™ (qualitative data analysis software). Verbal consent was obtained at the beginning of each interview. For those participants who preferred an interview in a language other than English, the cultural liaison translated the questions and responses.

Our plan to conduct fieldwork (including participant observation, focus groups, and interviews) in three South African provinces was

Table 1
Description of sample.

Demographic characteristics	South Africa (n = 36)
Mothers	
Mothers with albinism	3
Mothers with children with albinism	19
Rural	2
Urban	20
Employment Status	
Collective Income (i.e., mamas' groups)	1
Subsistence income (e.g., selling fruit, milling grain, sewing, soap making)	1
Collective and subsistence income	–
Employment income	8
Homemaker	12
Retired	–
Religious Affiliation	
Christian	21
Muslim	1
African traditional religions*	–
Other/ none	–
No answer	–
Stakeholders	
Occupation	
Healthcare providers (nurses, genetic counselors, dermatologist)	4
Social worker	1
NGOs	3
Faith Leaders	1
Journalist	–
Policy Makers	2
Teachers	–
Traditional Healers	2
Researchers	1
Albinism Status	
With albinism	5
Without albinism	9
Gender	
Female	8
Male	6
Religion	
Christian	8
Muslim	–
African traditional religions*	2
Other/ none	1
No answer	3

*While no participants identified ATR as prime religion, there was evidence of how ATR overlaps with mainstream religion in participant interviews and observation.

disrupted by the COVID-19 pandemic. Depending on pandemic restrictions at the time, some interviews were conducted in person with the facilitation of community-based researchers and a local cultural liaison, and others were conducted via digital platforms (zoom, WhatsApp). Contextual data were elicited through dialogue with academic and community researchers and cultural liaisons, viewing the environs of a community via Google Maps (street view), and asking additional contextual questions, such as: *What did your day involve prior to this interview?* and *Please describe the setting you are in. Who else is in the vicinity?*

Throughout the research process, and particularly during interviews with mothers impacted by albinism, we applied a trauma-informed approach, recognizing not only that trauma can be widespread (Shimmin et al., 2017), but would likely be more prevalent for the mothers in our study. We aimed for a conversational approach with questions such as: *What is it like for you to be a mother of a child with albinism?* *What was your experience of delivering your child(ren) with albinism?*

3.3. Data analysis

Data analysis occurred using NVivo 12™ software and involved line-by-line coding which progressed through levels of abstraction to

thematic analysis. Data were coded using a codebook established in Phase I (in Tanzania). Additional codes that surfaced in the South African data were added. Thematic analysis progressed through an iterative process of reviewing code summaries and transcripts, while memoing and team discussion, through increasing levels of abstraction. In keeping with critical perspectives and decolonizing research, the data were analysed from the mothers' standpoint (Harding, 2007; Lee & Evans, 2021), with close attention to the narratives they constructed about their experience and the social structures that impacted their experience. (See Table 2).

3.4. Scientific quality and ethics

Scientific quality was supported by applying Lincoln and Guba's (1985) requirements for qualitative research; namely the trustworthiness elements of credibility, dependability, confirmability and transferability. Credibility was ensured through triangulation and reflexivity; dependability through transparency about study processes (i.e., careful documentation of decision trails and project logs) and triangulation; confirmability through an audit trail and inclusion of data excerpts; and transferability through thick description and purposive sampling. Specifically, environmental triangulation involved data collection from various locations in two provinces (Gauteng and Northern Cape); on account of the pandemic participant observation as a form of triangulation was limited. Conducting data collection and analysis as a team (with more than ten researchers involved) served as additional forms of investigator triangulation, where different viewpoints were incorporated. As an interdisciplinary, intersectoral research team, additional theoretical triangulation was fostered. Reflexivity to account for the influence of our respective social locations included team meetings to discuss decolonizing methodology (Lee & Evans, 2021; Ndimande, 2012), and reflecting on power differentials in fieldnotes that were subsequently analyzed. Research ethics clearance was granted from four universities in Canada; Tanzania's National Institute of Medical Research and the Tanzania Commission for Science and Technology; and the University of Pretoria, South Africa.

4. Limitations

The limitations of the study related largely to the adjustments required during the pandemic. Because of limited travel, we could not immerse in the field (e.g., visiting peer support mothers' groups or

Table 2
Data analysis themes and sub-themes.

Themes	Sub-Themes
1. The life-defining experience of birthing a child with albinism	"I was so surprised": Mothers' responses to the birth of a child with albinism "That comment can destroy you": The immediate and sustained impact of healthcare provider responses to the birth of a child with albinism "You're going to go out and face the world with this child": Anticipating family and community responses
2. Equipping and supporting the new mother	"I was clueless": Access to accurate health education "It is uneven": Access to Genetic Counselling "It's a struggle": Access to Health Services and Government resourcing "Really filling a gap": The contributions of civil society organizations (CSOs)
3. Resolution and social discourses	"A blessing": Discourses about the child with albinism "Naturally strong": Discourses about the mother "Not always hands-on": Discourses about the father "We are equal": Human rights and equality

health settings) which would have facilitated the recruitment of mothers from rural and remote settings, as well as a larger and more representative sample of stakeholders. These limitations are offset by the breadth of expertise and representativeness of our team, who bring their “insider” knowledge to the interpretation of study findings.

4.1. Findings

The birth of a child with albinism for the mothers in the South African phase of our study (as for mothers in the Tanzanian and Ghanaian phases) was a life-defining moment. From the mothers’ standpoint (i.e., experience), findings revealed influencing factors, such as the health of the child, and the responses of the attending healthcare providers, the partner and family, as well as the community, any of which could change that moment and the subsequent parenting. Health education, including genetic counselling, was also pivotal in shaping the experience. The mothers described coming to a place of resolution where they had come to terms with, and in most cases, embraced parenting a child with albinism. The cumulative and gendered responsibility of parenting the child tended to land on the mother who often was left with minimal resources.

THEME 1: The life-defining experience of birthing a child with albinism

“I was so surprised”: Mothers’ responses to the birth of a child with albinism

Giving birth to a child with albinism was an immediate, life-defining moment for the mothers in our study. All expressed surprise at the birth (ranging from a few minutes of adjustment through to “shock” and denial) and talked about the cascade of emotions that followed. At one end of the continuum, one mother spoke of her great joy:

That day when I received my baby girl, oh it was a wonderful day for me. I was over the moon, I was happy because God blessed me with a baby girl. And a deeper blessing - the skin colour: “I have a child, a white baby girl.” I wasn’t disappointed. No, I was so happy (P29).

In contrast, another mother was immobilised by the news:

It was very scary, I was not expecting it. I cried when they told me that my child had albinism. Initially I told them that I didn’t want her. The way I was crying, they had to call the father to come and calm me down (P18).

This sadness persisted as the mother explained she was “crying, crying, crying for a year”. She described her initial response of being puzzled and then as one of denial: “I was surprised because there’s no one like this in my family, you know. I asked the doctor, “what is wrong with the hair?” She avoided caring for the child in the hospital, saying “no, this is not my child’ because I was still in denial”. Other mothers were confused about the birth with questions as to the cause. Some described feeling shame and self-blame. A stakeholder, who herself had a child with albinism and also offered support to mothers, observed:

To some mothers it’s still a shame. They think that children with that condition are not normal, or maybe you did not take care of yourself during pregnancy. Also, trauma, some mothers blame themselves for having child with this condition (P6).

Mothers’ immediate responses to the birth of a child with albinism involved framing the condition in relation to the child’s health and gender, and any family history or previous knowledge of albinism. One mother thought her child had died when she was told it was a “white baby”:

My doctor said, “you’ve got a white baby” and I looked at my partner, because I thought “what does he mean ‘white baby?’” I was panicking because he said, “white baby” and I couldn’t understand. And then she

came, I always say it was a bit shocking, but I was like “okay”. But then immediately I asked the question, “is she healthy?” And they said “yes, two feet, ten toes”. I said “perfect” (P36).

Similarly, another mother said, “I was relieved to have a girl” (P7). Knowing albinism was in the family helped with the sense-making; one mother said, “I think the father just adjusted so well because this albinism condition, they do have on his side of the family. Yes, so he was familiar with the albinism condition” (P20). Another said: “albinism has always been in the family. My auntie has albinism, and my cousin has a daughter who has albinism. So, yeah, it came as a shock to me that I had a baby with albinism, but then you know it wasn’t that amazing” (P13).

“That comment can destroy you”: The immediate and sustained impact of healthcare provider responses to the birth of a child with albinism

The surprise and immediate sense-making extended to healthcare providers, partners, families and communities, all of whom influenced mothers’ resolution to the reality of giving birth to a child with albinism. Mothers were tuned to the responses of the birth attendants (whether traditional birth attendants, nurses, midwives, or doctors) in the very moments of birth and then immediately thought of what the response of others would be.

I was so nervous because the nurses kept on asking each other- I couldn’t see the baby but they could see it and were asking each other “what do you think that is? Is it maybe a bum or what?” (P20).

The HCPs in this case were puzzled by the paleness (i.e. non-melination) of the baby’s head and hair, such that they thought it might be another presenting part. As in this excerpt, mothers were very aware of HCPs’ responses to the birth of a child with albinism. In an extreme case, the midwife rushed the child to the nursery and left the mother (P38) “in a pool of blood” without tending to the last phase of birth (the placenta). Without another physician happening by to intervene, the mother was “on her deathbed”. In other cases, though not as immediately life-threatening, the uncertainty, surprise or judgement of HCPs left mothers adrift in the moment and well into the future: “If nurses can be taught how to deal with that situation. Because that comment can destroy you, and then you have a problem forever” (P6).

Nurses too would draw on their lay knowledge about albinism, as explained by one CSO stakeholder: “people leading departments are human beings from the same environment where we grow up in South Africa” (P3). Some mothers were faced by HCPs’ judgement, stereotypes, and colourism, for example being asked whether they were dating a White man. Another mother who was involved in supporting other mothers said, “I’ve heard stories of nurses who shy away from giving you the child or it looks like “Oh my God, this child” and already that puts a negative thing in the parent’s mind” (P36). One mother overheard nurses saying, “what is this gold thing? They were asking each other, what is this colour? She is albino!” (P7). Some mothers told of their children receiving a lot of attention from nurses, in a positive sense, but also as a spectacle as nurses “fought over the baby” as to who carry it; “everyone wanted to see the baby” (P38). The response, thus, of a HCP at the birth of a child with albinism could exacerbate a traumatic experience or could put the family on a good track.

Overall, nearly half of our participants described the birth as positive. Positive support involved immediate encouraging responses about the child (e.g., saying “what a beautiful child”), simple explanations of the genetic condition (e.g., that both parents are carriers of the gene), basic teaching about the care of a child with albinism (e.g., skin protection), watchfulness about maternal attachment, and referral to dermatology and ophthalmology.

“You’re going to go out and face the world with this child”: Anticipating family and community responses

From the moment of birth, mothers worried about the responses of their families and communities, with comments such as “my only concern was what my family would say” (P30) and “the hardest time is for you to introduce the child to the community, to the family, their first reaction. After that, it’s good” (P18). Such worry was not without cause. In some situations, partners abandoned the mother or decreased their involvement. In one case, a mother explained that the husband listened to his colleagues who commented “Why did you have such a child? Maybe it was something your wife did” (P17). In this case, the husband left for some time. This mother was also told her child was the result of witchcraft. Another woman’s husband said when he learnt of the birth: “I don’t want anything to do with you” (P30), saying that the child was cursed. One mother was faced with a litany of accusations from her community:

Other relatives, oh, it was not easy. They were criticizing a lot. Telling me I must tell them who’s the father of the baby. Others were saying, “no, you’ve been eating mangoes too much. That’s why you gave birth to this....Don’t sit in the middle of the door, that’s why you gave birth to this little swine”. I was hurt. Doctors advised me to stop breastfeeding this child, because it was hurting me. And others said, “This one is not a baby, it’s a zombie, a Tokoloshe [a malevolent mythical persona-like animal of short stature].” Others say, “this one’s a toy that comes with batteries.” Then my sister’s son will come with a battery and put it in the Pampers. Obviously, when you do that, the baby will move. Then they say, “This is a toy, it is not a baby” (P5).

In these comments are evident gendered blaming for the condition and a range of dehumanizing myths in circulation (e.g., reference to a swine and zombies). In some cases of abandonment by husbands and in-laws, the mothers returned to their families of origin. In contrast to the negative responses, there were also exemplars of families and communities embracing the child with acceptance and joy, offering support and resources for childrearing.

Even if a family was supportive, mothers might still be ostracised by a community, as they went out to “face the world” with their child with albinism.

Family really did not have a choice, they were happy that I had a child with that condition; it was never a problem with the family. But I had a lot of challenge with the society, because people are talking. We’re from a village where, before my child, we had only one person with that condition. They were not used to albinism and so you would hear stories like “She had this kind of a child because she was dating a lot of men.” A lot of negative things. And at that time, I’m still new to that situation, I’m a new mother with my first child, so it was really difficult during the first phase (P7).

The stakeholder participants contextualised the mothers’ experiences, explaining how social structures in South Africa, such as gender-based violence, could amplify the difficulty faced by these women as they raised their children alone, not “waiting for the abuser who is the man” (P4). Another stakeholder was incisive about the intersecting sources of discrimination:

In South Africa, race really matters. As a black woman you are not safe at all. Whether you work or not, you’re not safe from a whole range of things. As a white woman you usually have more privilege and you often can buy your safety to some extent. If you have albinism, you have this race, gender, colourism and disability compounded intersectionality that really gives you very little agency to negotiate, to launch yourself from a positive. So, safety is a massive issue. And it’s not just safety as I say from having albinism, it’s safety just from being a woman, and then from being a black woman. You must probably live in areas where there’s a lot of violence generally. So, that’s really, I think for me, the overriding factor. If you don’t feel safe you can’t thrive and it’s as simple as that (P23).

Gender inequality played out along with a constant undercurrent of concerns for the safety and security of their child (e.g., “I’m always

scared” P37) and the struggle to provide for themselves and their children.

To summarise the first theme, the moment of birth of a child with albinism came as a surprise for all the mothers in our study. They engaged in sense-making processes to understand the birth which were shaped by the responses of healthcare providers, families, and their communities, in this way beginning their path to resilience. In the next theme, participants’ views on what could equip and support the new mother are discussed.

THEME 2: Equipping and supporting the new mother.

Participants were clear as to what could equip and support the new mother after the birth of a child with albinism, particularly health education, genetic counselling, and health and social resources provided by the government. Albinism NGOs filled the gap that resulted when such services were not accessible. This theme begins to build a multi-levelled picture of mothers’ resilience, as strengthened (or not) by structural and societal factors.

“I was clueless”: Access to accurate health education

Most of the mothers described themselves as having little knowledge about albinism, as reflected in the comment “I was clueless” (P20). One mother hoped that if she let the child cry long enough, they would change colour: “I thought maybe if he cries too much, he’s going to be darker again” (P19). Another mother thought that simply with time passing the child would change colour. When asked if they had received health education at the time of birth, only about one quarter had, and what they received was rudimentary. For example, they might be told they would need to see a specialist or a social worker, or that they should apply skin cream (sun protection).

With such absence or minimal teaching at the time of giving birth, mothers were left to secure their own information, with many of them “Googling” to find out about the cause and the care of albinism.

When I leave the hospital there was no one who told me that your child has albinism. They didn’t say anything about it. Yeah, so like there was no one who told me what must I do, what must I not do. So I Googled albinism (P29).

This left mothers feeling ill equipped for caring for their child, in the words of one mother: “I felt so heartbroken to a point where I didn’t know how to treat [my child]. I was just treating her with Johnson and Johnson and she reacted” (P33). When this mother “Googled” how to care for her child, she gleaned incomplete information. An albinism advocate reiterated this concern:

the government does not have easy access to information related to albinism whether it’s in hospitals or elsewhere, there is no information out there. So, at the end of the day, these parents have to wing it. If they hear that “oh, if your child is burnt, you need to put sunlight on their hands,” that’s what they do. So, at the end of the day, you get some of the most harmful acts being done to people with albinism by those who they love or their parents, because they don’t have information (P22).

Examples in our data of such harmful acts included sandpapering a black spot caused by sun damage. Due to the lack of information, mothers were found to bring their children to healthcare providers only when they were already experiencing skin damage. A healthcare provider said: “It’s unfortunate that most [mothers] come with kids who are already having some form of photo-damaged skin, when the child is older. They’re already experiencing problems” (P21).

Some mothers were given inaccurate information by healthcare providers, for example, that “God only knows” the cause of albinism. When a mother went to a doctor for a postpartum checkup, she was told that her child did not have albinism. Instead, she was told that “It’s only the colour for her now, she’s going to get her colour when she gets older” (P7).

The mother perceived that the doctor did not want to tell her the truth, perhaps to protect her, but as a result she was unprepared on how to take care of her child.

Health education should extend beyond the mothers' information needs. A healthcare provider explained:

Education doesn't only revolve around the mother but people around the mother as well and the community that the mother is from and then it becomes a process, you know. For a mother to start accepting that it's not her fault and also now...because all this negativity that comes toward the mother makes the mother be resentful to her own child, you know. So, it becomes a really a long process (P21).

Referrals, when made, were to a social worker, a genetic clinic (for resources, teaching, support), a counsellor/psychologist, and albinism NGOs. Rarely, referrals were also made for dermatology and ophthalmology as the mother was leaving the hospital or birth clinic, although those visits usually occurred as the child was nearing time to enter school.

"It is uneven": Access to Genetic Counselling.

In our sample, only one-third of the mothers had referrals to genetic counselling, for the most part because of the challenge of availability for those in rural or township settings where there are no genetic counselors and needing to commute long distances to reach the genetic clinics. A stakeholder (policy maker), described the predicament faced by those in remote settings, and advocated for home visits in such cases:

In the rural areas they have to travel a long distance before they get to the clinic. Sometimes it's raining, sometimes the conditions for the mothers are too onerous to walk that long distance. The Department of Health should create home visits by those tracking children with albinism (P25).

Another identified need was prenatal information, as this stakeholder explained: *"It is painful, because up to now, South Africa has not prepared a woman with albinism or who is pregnant, to say there is a possibility of you getting a child with a genetic condition" (P4).*

For those who were able to access genetic counselling, typically free of charge in urban settings, it provided reassurance, especially knowing the genetic cause of albinism and education about skin and eye care, as well as referrals and resources; *"their outcomes are better" (P22)*. Mothers who had this kind of support seemed well-adjusted and bonded with their children. In addition to having the confidence and resources to care for a child with albinism, mothers seem to feel assured knowing that they can explain the condition to their families and community. A long-time provider of genetic counselling remarked on the *"huge shift in the management (of albinism), and in the attitudes and acceptance for themselves, their babies, and certainly in the schools" (P39)*.

"It's a struggle": Access to Health Services and Government resourcing.

Along with health education at the time of birth and access to genetic counselling, mothers' experience could be much improved if they had access to health services for skin and vision care. An NGO leader put it bluntly:

South Africa has not reached a level where we say we are able to access services for children with albinism or PWA. It's a struggle to access a medical facility in our country and the proper care because look albinism is a condition that needs to be managed by a dermatologist and an eye specialist (P3).

A dermatologist emphasised the importance of an early skin assessment in the first year, followed by regular visits, rather than intervention once skin lesions are present. And yet, in their experience, very few young children with albinism were seen because there are few dermatologists serving the public health system (i.e., most work in the private

system). A basic concern mentioned by most mothers was the difficulty in accessing sunscreen, often having to pay out-of-pocket. A decade ago, at a 2013 albinism roundtable, NGOs prepared a government recommendation to have sunscreen for PWA provided as part of public healthcare but years later, they are not aware of movement on this front.

Access to services was even more difficult for those outside urban centres:

Access to health care in South Africa is very unfairly advantaged towards people in bigger cities. And that's definitely the same with albinism, which is why the myths and non-scientific explanations are more common in rural areas because they haven't had an alternative explained or presented to them (P8).

Some mothers of children with albinism also had difficulty accessing the government social or disability funds (such as the South African Care Dependency Grant) because they might encounter a frontline government worker who would *"interpret"* (P2) albinism as not being a disability, and thus not eligible for funding. We learnt in discussion with a policymaker that mothers have a higher chance of qualifying if the child has *"visible albinism presentation"* (P22), meaning those who have pale skin and hair with visible spots on the skin. The acceptance to qualify varied, however, by the officer handling their case. Thus, some districts or provinces might have higher rate of acceptance than others. Mothers were not informed about the opportunity of an appeal to re-evaluate the assessment if they were denied. The lack of access to these funds is unfavorable to mothers as they were further burdened by poverty and limited to the access to much needed resources.

"Really filling a gap": The contributions of civil society organizations (CSOs).

Many mothers explained how CSOs filled the gaps left by access to accurate health information and government services, as captured by this participant:

Most of the information you get from your NGOs. Those are the primary distributors of information. There are many such organizations, but they also lack in capacity. They cannot reach everyone, they can only do what they can, and most of them are centred in urban areas. So, at the end of the day we have a group of mothers scattered everywhere across South Africa who do not have access to what they need (P22).

Peer support groups (typically initiated or facilitated by a CSO) were important resources. As put by one mother: *"I never got anything from the hospital, there is nothing that beats the support groups because we have the same kids. To be with the same mothers, you help because you get more information" (P35)*. Examples of peer support included a "disability group", a WhatsApp group, and an advocate who sought out and visited mothers who had given birth to a child with a disability (such as albinism). Through peer support, mothers received tips on the care of their child, access to sunscreen, assistance in accessing skin and eye clinics, and much moral support. One mother described how she encouraged other mothers in such a peer support context:

And I always tell the mother, "you are so brave, because you are a mother, you've been through the worst of the worst. And you accepted every remark, every question, every name-calling, every pointing of fingers, but I'm not going to let somebody define the person that I am." (P14).

Faith communities were also a source of support, though this resource was not as foregrounded as in the Tanzanian context (Reimer-Kirkham, Strobell & Buyco, 2022). A participant explained how a faith community could support a mother of a child with albinism:

The responsibility of the church with regards to any child with albinism, or any woman who was left by a husband or a boyfriend on the basis of the condition of the child, the responsibility of the church is to love the child.

And when you love the child, it means that you need to look after the child. You need to support the mother psychologically when she's going through any problems. If she's stressed out the church leaders or female elders need to speak with her. If there's no support helping her, then she must be referred to the relevant qualified person (P15).

To summarise the second theme, there was inconsistency in the types of resources and support available for mothers of a child with albinism. Access to accurate health education, genetic counselling, and health and social services was often incomplete or absent altogether. Civil society organizations, peer groups, and faith communities were vital in filling the gaps for the mothers in our study.

Theme #3: Resolution and social discourses.

Mothers in our study came to acceptance or resolution about the birth of their child with albinism, often on a trajectory from surprise to trepidation to compassion to courage. Giving birth to a child with albinism came as a shock to some mothers, whilst some of the mothers experienced love, support and compassion from family members and the community towards their children with albinism. The portrayal of these virtues gave them courage to accept and love their children as well. To do so, they drew on social discourses about the child, themselves as mother, and about the father, often with a degree of inevitability or fatalism, as reflected in the comment, *"because your child is going to be your child"* (P14).

"A blessing": Discourses about the child with albinism.

Some mothers understood their children as God's gift or blessing, which they said helped them transcend concerns or problems. One said:

I don't have any worries. After all it's God's will. He's the one who said I must have that kind of a child, and so I don't have any problem with it, and so I won't change it, I can't change it, she's there, so, there's nothing. The only thing I must do is to look after her and love her and give her all my love. If I take good care of that child and everything will be okay (P11).

With these words comes a degree of fatalism and a kind of acceptance as there is no other choice but to love the child. Another portrayal of the child with albinism was that of being rare or special even as they also carried concern for the child, as depicted in this comment: *"I'm enjoying every moment with her, she's very special. I can't say I've got any regrets or anything that I have a baby with albinism"* (P13).

There was a strong storyline of parenting a *"normal child"*, an explanation that helped mothers come to terms with their condition, as depicted by P11:

If you have an albinism child, you're still a mother and that child, she's a human being, or he's a human being. There's nothing wrong with her, it's just that their skin colour is different from others but you must take care with her, you must treat her with respect, love her, like take good care of that child and everything will be okay (P11).

"Naturally strong": Discourses about the mother.

Although having a child with albinism was constructed in a positive light by the mothers (even if not so by family or community members), narratives about mothers suggested that something extra was nonetheless required from them. They were described as innately capable with a *"nurturing instinct"* (P15), and as being *"created"* to withstand the negativity and opinions of a community. One mother described herself as an *"umbrella, to always be there for her kids."* (P17). A pastor said, *"our mothers are the rock of our nation"* (P15). Many examples showed mothers as human rights defenders, standing up against discrimination, *"fighting"*

for services, and sacrificing to provide opportunities for their children. One of the stakeholders (a social worker) was insightful in observing this discourse of the *"strong woman"* as being socially constructed and not supportive of mothers impacted by albinism:

We have normalised that women must be strong, women must face all the challenges of the family, women must bear them and so forth. When these mothers then face challenges with their children, the challenges of stigma, they just take it as a normal part of being an African woman. And therefore, they don't see any need for counselling and so forth, they just try to be strong and resilient, but at the end of the day it also impacts them greatly. And also, mental services in South Africa, it's also already an issue (P22).

Another stakeholder astutely observed that the strong mother motif could inadvertently discourage seeking mental health support: *"In South Africa, it's not actually okay to say that you're struggling after having a baby because you've had your baby you should be happy"* (P8).

"Not always hands-on": Discourses about the father.

In contrast to the *"strong"* mother discourse, fathers were described as less involved, in the words of one mother (P5): *"it's a huge difference when it comes to the mother and the father"*. It was not unusual to have fathers themselves or others raise the question of whether the child with albinism was theirs, or suggest that the child was cursed (P30). This characterization of fathers as having *"different worries"* (P16) and *"not always hands-on"* (P13) was portrayed as innate or natural. A few mothers offered exceptions to this stereotype, with one father described as *"more attached to the child than the mother"* (P5), and another situation in which a mother (P19) described her partner wanting to attend the genetic clinic with her and as a result they had confidence in caring for the needs of their children with albinism.

"We are equal": Human rights and equality.

With the cumulative responsibility of parenting a child with albinism falling on mothers, their day-to-day experience (i.e., their resolution to the realities of mothering a child with albinism) was characterised by heightened alertness, deprivation, and challenge. They were the ones to advocate for skin and vision care, they were the ones to buffer discrimination, and they were the ones *"worried my child may be stolen"* (P12). Several noted they never felt safe, in the words of P18 *"because there are still people in Africa with ritual beliefs that there is something special with children with albinism"*. Their worry was compounded by issues of poverty, food insecurity, and social exclusion. In the words of P14, *"To be honest, [poverty] hits hard, it hits very hard. Because you ask yourself, I have this child and I have no income. How am I going to support this child?"* Because of the stigma of albinism, they might be excluded from community activities like food gathering.

Another study participant pointed to the gap between policy and its implementation:

The South African Bill of Rights protects everyone in fact, including women. Everyone must have access to employment, everyone must have access to freedom of speech, everyone must have access to economic participation, health care and all these other things. But for women now, these things are really not translating to what is on the ground. A lot of women are not enjoying those rights and it even makes it worse if you are a black woman who is poor living in a remote area. If you have a child with a disability, it even makes it worse because your voice is not heard and you become the last preference whether it's an intervention, whether its policies delivered for targeted and vulnerable groups, you don't even come into mind. So, at the end of the day, these women remain at the far margins of society. (P22).

Yet, there was some optimism that social change is coming about that will benefit mothers of children with albinism. A stakeholder described

the tension between existing inequalities and the fulfilment of human rights:

You still have inequalities at work. You still have women not heard. So many, many, many other rights of women in South Africa are not being considered and it's a concern. Hence, in South Africa you find there's many, many women's groups who are trying to say, "let's have a conversation, we are women, we are equally educated, we are equal, and therefore let's just be treated with respect and dignity" (P22).

Summarising the third theme, sense-making strategies employed by mothers as they came to terms with having a child with albinism reflected social discourses about the blessing of having a child, the strength of a black mother, and the acceptance of limited involvement of a father. Yet, their mothering was typically marked by worry, poverty, and social exclusion. Gaps between government policy and implementation exacerbated gender inequality. In this context, mothers' resilience involved their adaptation to adversity, especially when given gender equality, respectful maternity care, access to health information, and the embrace of their families and communities.

5. Discussion

5.1. Comparative and historical analysis

As a first point of discussion, our findings are similar to, yet different from, Kromberg's (1985) study four decades earlier. The initial shock and disorientation, the impact of family and community responses, and the period of resolution were similar. Compared to Kromberg's (1985) findings, mothers in our study were less likely to rely on superstitions / myths in their sense-making, though they were still confronted by them, especially in rural contexts. Most mothers held both a basic genetic understanding and a spiritualised understanding (e.g., albinism as "God's will" for their child). Birth has become more medicalised in South Africa, and some mothers now have access to genetic counselling. Access to health information remains inconsistent, even as the internet has become a common source of information. Also a matter of access and as previously found, those in rural and remote areas have less access to services. Infanticide and attacks may have been hidden and only whispered about at the time of Kromberg's (1985) study. Mothers today are vigilant about keeping their child with albinism safe, well aware through news outlets and social media of reports of violent attacks against PWA.

There has been much social and political change in post-apartheid South Africa in the decades since Kromberg's first study on mothering and albinism (Kromberg et al., 1987). Now a middle-income country, declining child poverty and maternal mortality rates have improved circumstances for PWA overall. Few studies exist on mothering and albinism, but where such research has been conducted, there are strong similarities in the pivotal nature of the birth of a child with albinism; the impact of negative reactions from families, communities, and care providers; the general lack of education about the care of a child with albinism; and the influence of myths and stereotypes. In contrast to studies in Uganda (Taylor et al., 2021), Tanzania (Reimer-Kirkham et al., 2020; Strobell, 2020), and Malawi (Likumbo et al., 2021), mothers in our South African study were more informed as to the genetic cause of the condition and less impacted by myths and superstitions, a finding that suggests the growing momentum and positive influence of South Africa's relative socio-economic stability, progressive health system and policy frameworks, genetic counselling, health professions education, and albinism advocacy over the years.

5.2. Human rights and gender analysis

A second point of discussion applies a human rights lens to the mothers' birthing stories, in relation to gender equality (particularly, gender-based violence and respectful maternity care) and the right to

health through health systems and access to accurate health information. This lens builds a multi-level interpretation of resiliency as extending beyond the typical individual-level focus on a person's adaptation to adversity, to community- and social-levels to uncover pathways such as gender equality, strengthened health systems, and access to respectful maternity care and health information, all of which contribute to the security and well-being of mothers impacted by albinism.

Gender analysis helps recognise, understand, and make visible the gendered nature of the experiences of mothers affected by albinism to see the different ways in which mothers' human rights are impacted based on their birthing stories. The human rights that are in question here are gender-based discrimination, gender-based violence (including obstetrical violence), gender equality, and harmful practices at the intersection of gender, disability (in South Africa, albinism is recognised as a disability) and colour (Kromberg & Kerr, 2022). This intersectional approach is rooted in the various relevant international treaties, notably the Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW, United Nations, 1979) and the Convention on the Rights of Persons with Disabilities (CRPD, United Nations, 2006).

Drawing on the evidence that emanated from our research, mothers impacted by albinism experience harmful practices that impose on the full and equal enjoyment of their human rights as required by the Constitution of the Republic of South Africa (Act 108 of 1996) and the Bill of Rights in the Constitution (South African Government, 1996). Section 7(2) of the Bill of Rights compels the State to respect, protect, promote and fulfill the rights in the Bill of Rights, including the right to equality, human dignity, life, freedom and security of the person, and health care. The Bill of Rights also specifically enshrines the rights of children to care, health care, and social services. Discrimination against anyone based on gender, colour and disability, amongst other listed grounds, is prohibited in Section 9(3) of the Bill of Rights in the Constitution of South Africa.

5.3. The right to health and health information through strengthened health systems

The right to health requires health systems (as the duty bearer) to assure the highest obtainable standard of health for their populations (the rights holders) based on four benchmarks: availability, accessibility, acceptability and quality (World Health Organization, 2023). It is the sole responsibility of the health sector to provide access to discrimination-free health facilities, goods and services and the equitable distribution of all health facilities, goods and services. Mothers impacted by albinism have the right to receive these goods and services in a non-discriminatory and supporting environment. It is clear from the findings of this study that mothers experience structural, systemic, and interpersonal discrimination in the health care system and on the level of the health care facility and provider. The concomitant harmful effects impact the mothers' lives, their babies' lives, and their families not just at the point of birth of the child but across the lifecycle of the person with albinism and their families.

In response to persistent advocacy supported by a body of research about women's experiences of disrespectful maternity care—with reports of lack of compassion, mistreatment, abuse, humiliation, and being subjected to inhumane, poor quality care during delivery (Bradley et al., 2016, 2019; Chadwick, 2019; Chadwick et al., 2014; Hastings-Tolsma et al., 2018; Hofmeyr et al., 2014; Malatji & Madiba, 2020)—a promising practice recently integrated into South Africa's policy context (and by strong WHO recommendation) is that of Respectful Maternity Care. The South African National Department of Health's (2021) *Maternal, Perinatal and Neonatal Policy* provides the context for assessing 'Disrespect and Abuse' and establishing guidelines to implement Respectful Maternity Care (RMC) in the health systems at a national level (Daniels, 2021). The World Health Organization (WHO, 2018) describes RMC as the care provided to all women in a way that promotes privacy, dignity,

and confidentiality, highlighting autonomy, the freedom from harm and mistreatment, and ongoing support during labour and childbirth.

Like mothers impacted by albinism in Tanzania (Ero et al., in press; Reimer-Kirkham et al., 2020; Strobell, 2020), Uganda (Taylor et al., 2021) and Malawi (Likumbo et al., 2021), mothers in South Africa too benefitted from timely access to health information as key social determinant of the right to health (Reimer-Kirkham et al., 2020). Recent scholarship has recommended genetic counselling to provide health information about albinism (Kromberg & Kerr, 2022; Taylor et al., 2021). The timing of genetic counselling is important, and early counselling soon after birth can be beneficial (Morris et al., 2015). For this reason, all those health professionals who attend at the birth or are consulted after it (including traditional healers) should be well informed, so that accurate and appropriate counselling can be offered (Kromberg & Manga, 2018) as to the cause and care of the condition of albinism. See Table 3. Emerging ethical considerations for genetic counselling and albinism arise from the “expressivist objections” (Boardman & Thomas, 2022; Burke, 2021) of disability rights activism, about possible inferences that conditions such as albinism is undesirable, deficient, and to be prevented. Thus, those offering health education and genetics counselling carry the responsibility of doing so from a stance of inclusivity, to provide parents with balanced information about living with albinism and support to prepare for raising their child” (Dive & Newson, 2022).

6. Conclusions and recommendations for best practices

Mothers’ birth stories reveal the delivery of a child with albinism as a life-defining moment, significantly changing the trajectory of motherhood as one anticipated it. Through sense-making and information-seeking, they came to a place of resolution that allowed them to embrace motherhood. The findings must be interpreted through the lens of human rights, particularly those of gender equality and the right to health and health information. Where progressive health and social policies exist and are implemented in South Africa, mothers and their children with albinism can thrive. Based on evidence from this study, our program of research, and the work of the UN Independent Expert on Albinism, the following Best Practices are recommended:

Best Practices for Health and Social Services.

1. Respectful maternity care at the time of birth, with sensitivity to the discrimination and worries a mother is facing (WHO, 2018).

Table 3

Genetic counselling.

Genetic counselling services are defined as “the process of helping people understand and adapt to the medical, psychological and familial implications of the genetic contribution to disease” (Resta et al., 2006, p. 79). Genetic counselling should help the individual or family to:
(i) understand the medical facts, diagnosis, prognosis and management of the condition
(ii) appreciate the genetics and risk of recurrence in relatives
(iii) understand the options available for dealing with the risk
(iv) make the best possible adjustment to the condition
Genetic counselling should be client-centred and non-directive, so that the recipient is empowered to use the genetic information in a way that will increase personal control, reduce psychological stress and encourage meaningful decision-making (Kessler, 1998; Kromberg et al., 2013). When counselling is provided for families with a member with albinism, the informed genetic counsellor (see Kromberg, 2018) should address various additional issues (Kromberg & Jenkins, 1984):
(i) A clear description of albinism, the cause and basic genetic defect, mode of inheritance, possible complications such as poor vision and skin lesions, treatment (necessary from early on to minimise side-effects) and prognosis
(ii) The death myth (so that the myth does not cloud the acceptance of the genetic factors involved), and that death is a natural and an inevitable fact
(iii) Community attitudes (and marriage, as few people with albinism marry), misconceptions, stigmatisation and marginalisation.
(iv) Vocational guidance (since jobs in sunny situations should be avoided)

2. Immediate health information about albinism as a genetic condition, with gentle exploration of family history and reinforcement of both parents as carriers, and basic care of the child (skin/eye protection).
3. Involvement of the father in health education, for family- and community-centred care.
4. Referrals to skin, eye, and genetic counselling clinics, and easy access to sunscreen provided through government-funded public healthcare.
5. Peer support, facilitated through local CSOs. Hospitals and clinics should have CSO contact information at hand.
6. Expanded and easily located social media and internet resources about care of a child with albinism.
7. Trauma-informed care considering violence targeted to women and children with albinism, including (i) intimate partner violence after the birth of a child with albinism, (ii) discrimination and/or abandonment by partner, family and community, (iii) sexual violence based on fetishization of the condition and (iv) attacks and killings that are based on mystification of the body of PWA (Shimmin et al., 2017; United Nations General Assembly, 2020).
8. Follow-up care with assessment for maternal attachment and post-partum depression; with access to mental health counselling.
9. Genetic counselling services added to all health clinics offering comprehensive services, such as skin and eye care, specifically for people with albinism.
10. Meaningful involvement of mothers impacted by albinism in their direct care (i.e., person-centred care) and meaningful consultation about services and programs specific to mothers impacted by albinism (i.e., patient partners or patient engagement).
11. Health Professions Education about albinism for birth attendants (doctors, nurses, midwives, traditional birth attendants).
12. Community education on albinism to counteract the effect of beliefs which often lead to the unjust marginalisation of people with albinism and their families.
13. Advocacy for disability benefits or financial aid for families with a child with albinism, as a poverty mitigation strategy and as access to immediate and concrete support for vision and skin care.
14. Integration of gender equality policies (e.g., sexual and reproductive health) into health and social services.
15. Support mothers of children with albinism as human rights claimants (including the International Covenant on Economic, Social and Cultural Rights (UN, 1966); Convention on the Elimination of All forms of Discrimination against Women (UN, 1979); Convention on the Rights of the Child (UN, 1989); African Charter on the Rights of Women in Africa (Maputo Protocol, African Union, 2003); Constitution of the Republic of South Africa (South African Government, 1996).

CRediT authorship contribution statement

Sheryl Reimer-Kirkham: Conceptualization, Methodology, Formal analysis, Investigation, Writing – original draft, Supervision, Project administration, Funding acquisition. **Barbara Astle:** Conceptualization, Methodology, Formal analysis, Investigation, Supervision, Funding acquisition, Writing – review & editing. **Jennifer Kromberg:** Conceptualization, Formal analysis, Writing – original draft. **Innocentia Mgi-jima-Konopi:** Conceptualization, Formal analysis, Investigation, Supervision, Writing – review & editing. **Ramadimetja Shirley Mooa:** Conceptualization, Formal analysis, Writing – original draft. **Maretha de Waal:** Conceptualization, Formal analysis, Writing – original draft. **Meghann Buyco:** Formal analysis, Investigation, Data curation, Project administration, Writing – review & editing. **Ikponwosa Ero:**

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