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The Situation of Mothers Impacted by Albinism in sub-Saharan Africa: A Video Analysis

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ABSTRACT

Background and Aim: First-hand accounts of human rights violations are increasingly being shared in video format, and researchers are steadily tapping into these mainstream videos as sources of research data. A population group facing stigma, trafficking, mutilation and killings is persons with albinism (a rare genetic condition) in Africa. Mothers of children with albinism carry a disproportionate burden in protecting and providing for their families, often in life circumstances of stigma and poverty. The *Mothering and Albinism* project was established to address their experiences.

Methods: Our international team of multidisciplinary undergraduate students conducted content analyses on fourteen videos that feature and described mothers and their experiences of giving birth to a child with albinism and how they navigated their lives in Sub-Saharan Africa.

Findings: The videos were thematically characterised by the varying experiences of mothers and the prominent responses of fathers, families, healthcare providers and the community that impact how mothers then move forward in raising their children with albinism. Factors such as the unavailability of health information and persisting misunderstandings about the condition accounted for the negative experiences of mothers and families.

Conclusion: Our findings suggest that public education is needed to improve responses of families, healthcare providers and the community, allowing for referral to local resources, improved management of the health issues faced by persons with albinism, and less blame attributed to mothers for their child's albinism.

Introduction

The Netflix film, "Can You See Us?" (2022), directed by cinematographer Kenny Mumba, offers an inspiring depiction of Joseph, a boy with albinism, navigating life amidst systemic prejudices and cultural discrimination in Zambia. This film is an excellent example of how videos feature important issues such as the challenges faced by persons with albinism (PWA). Through Joseph's journey, the film highlights the ostracization faced by PWA while celebrating their courage and resilience in persevering through hardship. In an attempt to capture similar stories, this paper describes a video analysis conducted by undergraduate student interns on mothers' experiences of giving birth to a child with albinism and

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how they navigate their lives in Sub-Saharan Africa. The analysis of publicly available videos aims to illuminate the situations faced by PWA, such as the gaps in healthcare provision. The video analysis is embedded in a larger study investigating a human rights and equity-oriented response to birth stories of families impacted by albinism in sub-Saharan Africa, and contributes to the *Mothering & Albinism* research program (www.motheringandalbinism.com) committed to addressing the unique challenges faced by families affected by albinism.

Background

Two primary aspects characterize the experience of PWA, namely, the physical implications of the condition and society's response to these physical implications. Albinism refers to groups of non-contagious, genetically inherited, recessive conditions present worldwide that reduce or inhibit melanin synthesis (Kromberg et al., 2023). Decreased melanin synthesis alters skin pigmentation and vision, resulting in poor visual acuity, a lighter complexion, and an increased risk for skin cancer (Kromberg et al., 2023). As oculocutaneous albinism is the most prevalent autosomal recessive condition in sub-Saharan Africa and possesses manifestations visible to society, most research in the area focuses on this subtype (Kromberg et al., 2023). The physical manifestations have led to harmful mythological beliefs about albinism such that albinism is contagious or that having intercourse with a PWA could cure HIV/AIDS (United Nations General Assembly [UNGA], 2022; Reimer-Kirkham et al., 2019). Beliefs continue to circulate that PWA are good luck, and witch doctors use their body parts for ritual practices (Taylor et al., 2019). PWA therefore have limited access to healthcare, increased incidences of mental health challenges, and increased incidences of abuse, including rape (Reimer-Kirkham et al., 2019). They also encounter social and cultural barriers related to poverty, colourism, and gender-based violence, in addition to being poorly understood and insufficiently protected by the government and justice system as a result of the condition (UNGA, 2022). Media coverage of reports on the attacks against PWA brought worldwide attention to these rights violations. With a desire to protect the rights of PWA, in 2015, the United Nations Human Rights Council appointed an Independent Expert on the enjoyment of human rights by persons with albinism, marking the beginning of an albinism human rights movement (UNGA, 2016). This movement has proven particularly important for structurally vulnerable populations, especially women and children impacted by albinism. Violent and discriminatory acts faced by PWA, as expressed by the first United Nations Independent Expert (UNIE), Ikponwosa Ero, "[are] disproportionately borne by women with albinism and mothers of children with albinism" (Ero et al., 2021, p. 89). Due to poor education on the etiology of albinism, mothers, upon delivery of a PWA, are often accused of being cursed or unfaithful leading to reports of excommunication by their husbands and communities. With this mandate to address human rights violations against PWA, the UNIE and supporting advocacy groups have produced publicly accessible educational videos that accompany their reports to the United Nations, ensuring that accurate information is accessible to all (Independent Expert on Albinism, 2024). The intention is that widespread education can eliminate misunderstandings and achieve health equity for this population.

Literature Review

The Birth of a Child with Albinism

Birthing a child with albinism is a life-defining event for the parents that is highly contingent upon the responses of family members, society and healthcare providers (HCP) (Taylor et al., 2021). In studies exploring mothers' reactions to delivering a PWA across multiple Sub-Saharan countries, mothers were unified by their surprise at delivering a child with albinism despite variances in incidence in their areas, access to accurate information, and resources available to them (Likumbo et al., 2021; Ngula, 2022; Reimer-Kirkham et al., 2024a; Taylor et al., 2021). Ngula (2022), a researcher in Namibia and mother affected by albinism, states, "when a child is born with complications or disabilities, it is devastating news- and especially when it is a child with albinism, who stands out because of their skin colour" (p.1). Despite negative initial responses, mothers have been found to transition from shock to acceptance (Likumbo et al., 2021; Reimer-Kirkham et al., 2024). A catalyst in the journey to acceptance of mothers affected by albinism is knowledge about albinism either present prior to or provided after birth (Reimer-Kirkham et al., 2024). A genetic explanation of albinism can absolve mothers from the blame of their child's condition. Even so, mothers remained vulnerable to society's misconceptions about the etiology of albinism. Whether the misconceptions led to accusations of infidelity or having mistreated a PWA previously, a mother highlighted her reflections upon seeing her child: "I experienced endless uncertainty… I was asking myself whether I had ever laughed at somebody with albinism" (Ngula, 2022, p. 2-3). During this unexpected situation, the response of HCPs was highlighted as either a damaging or healing force. A

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Ugandan mother recounts her experience of a HCP heightening her fear stating, “When I was producing that child, the nurse saw the child coming out and shouted, ‘what’s this lady producing?’” (Taylor et al., 2021, p. 4). While some mothers were left unsure of their situation, others recounted HCPs’ encouraging responses like, “What a beautiful child,” providing simple explanations of the condition, explaining how to care for a PWA, and connecting them with resources including genetic counselling (Reimer-Kirkham et al., 2024, p. 4). Such actions resulted in mothers reporting positive birthing experiences.

Video and Media Depictions of Albinism

The depiction of PWA in Tanzanian and other sub-Saharan African media is deeply shaped by prevailing negative societal attitudes (Brocco, 2015, 2016; Reimer-Kirkham et al., 2019). This bias is particularly noticeable in language used to refer to PWA. Despite ongoing advocacy efforts, derogatory terms including *“zeruzeru”* and “*mlangala*”—meaning ghost and white person, respectively—are still widely used by community members (Brocco, 2015). Such labels create fear that propagate crimes against PWA, including assault, murder, and commercial exploitation of body parts, to persist (Brocco, 2015). The portrayals of PWA in movies as mythical or antagonists reinforce harmful stereotypes, rather than advocate for inclusivity and protection (Brocco, 2016). Additionally, media portrayals amplified by Hollywood’s movie industry of PWA as violent, troubled, and genetically inferior can lead to PWA internalizing such damaging ideas, negatively impacting an individual's self-esteem (Burke et al., 2014; Acacia, n.d.).

There are, however, emerging efforts to counter discrimination through measures aimed at safeguarding the rights of PWA. Media outlets play a crucial role in these initiatives by promoting positive representations and using respectful terminology, such as “*maalbino*” or “*wat mwenye ualbino*” (meaning individuals with albinism) (Brocco, 2015). Media streams showcasing the resilience of PWA can shift the narrative toward celebrating diversity and fostering social harmony. While some progress has been made, significant challenges remain and the discrimination and exclusion faced by PWA continues to be seen (Vanguard, 2024; Mirilla, 2024). Comprehensive policies are essential to addressing deep-seated structural injustices that hinder access to education, healthcare, and employment opportunities (Brocco, 2016). The media’s role is vital in raising awareness, challenging discriminatory beliefs, and improving access to public services. Thus, this video analysis was informed by how media representations of PWA affect public perception while identifying both harmful stereotypes and emerging positive narratives that can drive social change. As advanced by the Office of the United Nations High Commissioner for Human Rights (2019), the portrayal of PWA in the media mirrors broader societal attitudes, indicating that the achievement of transformative change requires a concerted effort to reshape such narratives and cultivate a culture of respect and empathy.

Methods

This video analysis was a branch of a larger participatory systematic review project (see protocol with Open Science Framework: https://osf.io/eav73). The review question for the larger research project was: what are the experiences surrounding the birth of a baby with albinism for the family members and their carers in Sub-Saharan Africa (mothers, families, care providers/birth attendants)? The participatory systematic process was informed by six virtual meetings between January and October 2023 with stakeholders, including mothers affected by albinism, nurses and midwives, nursing educators, and albinism advocates (this process will be explained in a forthcoming paper). An integrative review was used, allowing the inclusion of various sources such as videos (Toronto & Remington, 2020; Whittemore & Knafl, 2005). The research team recognized the value of videos, as they can highlight first-hand experiences in their natural contexts. As a result, we, as multidisciplinary undergraduate students, conducted a video analysis to contribute to the larger research project and synthesize information about birth experiences, as well as the subsequent everyday lived experiences.

Researchers have conducted video analyses, such as evaluations of the accuracy and quality of information presented on platforms like YouTube which have exponentially become used (Azak et al., 2023; Chang & Choo, 2022; Eroglu & Altinli, 2022). Videos have been widely used for advocacy and health-related education as lay individuals benefit from their accessibility and their convenience for visually presented information (Yavan & Gökçe, 2022). Video-based educational interventions have the potential to raise public awareness and inform policy movements, thus supporting families impacted by albinism.

Inclusion and Exclusion Criteria

Videos that met our inclusion criteria discussed the following: (1) the birth of a baby with albinism spanning the perinatal period to early childhood, (2) the experiences of mothers, partners, other family members and birth attendants, including midwives, nurses, doctors and traditional birth attendants present during birth, and (3) a sub-Saharan Africa context. No date or language limits were applied and

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videos of varying duration were accepted.

Procedure (Search Strategy, Study Selection, Quality Assessment, Extraction, and Analysis)

With the assistance of an academic librarian, a search was conducted on YouTube and Vimeo as these represented the most common video platforms used for educational and information-sharing purposes. The searches occurred on May 24, 2023. To gather relevant videos, keywords included albinism-related search terms (as well as albino), Sub-Saharan Africa, mothers, fathers, families, and HCPs (for example, "albinism Africa mothers"). Due to many results with poor relevance, the first 100 videos that appeared from each search were assessed and sorted by relevance. Videos that were relevant were watched in their entirety for eligibility, with a final selection of 14 videos to be included in the analysis.

Data extracted from the videos included categories such as country publication date, focus, and author/producer/source of the videos. A matrix (Garrard, 2020) was used for analytical data extraction using additional categories tailored to better answer our research question. The additional categories included (i) responses of mothers, partners, families, communities, and HCPs to the birth of a child with albinism, (ii) supportive and unsupportive factors that influence the birthing experience, and (iii) recommendations that best support mothers and families impacted by albinism. A video content analysis was undertaken to identify themes and patterns within the data (Macnamara, 2005). Content analysis is an analytic approach ranging from impressionistic and intuitive analyses to systematic textual analyses (Polit & Beck, 2021). Qualitative content analysis is defined as "any qualitative reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meaning" (Patton, 2015, p. 541). In descriptive qualitative studies, content analysis of narrative data is used to identify prominent patterns and themes to make meaning. Each video was assigned to one undergraduate student. Then, a different undergraduate student, accounted as the checker, was tasked to each theme to review and summarize the data, revisiting the videos multiple times to fill in gaps. Regular meetings were used for analysis and confirmation of interpretations with the group, guided by the supervisors (SRK and BA).

Evaluation of the Videos

The Global Quality Scale (Table 1) is a tool used to assess videos' validity by scoring videos numerically out of five with one representing a poor source with poor flow and five representing a smooth video that summarizes key information (Li et al., 2019). The videos included in our study were rated on the Global Quality Scale, with an average poll score of 3.357/5. As a second, complementary tool, the DISCERN instrument was used to assess aims, relevance, sources, date of publication, balance and bias, additional sources, areas of uncertainty, and overall quality of source (Charnock et al., 1999). Each video was assessed by one author and a checker (MB). Since included videos represent mothers', families', and HCPs' lived experiences, no videos were excluded based on quality. Quality appraisals were considered during analysis; however, relevance-based inclusion was preferred.

Limitations

Media platforms like YouTube and Vimeo are excellent resources for knowledge dissemination on public health issues as they are widely accessible and can reach a broad range of audiences. They, however, should be used with caution as there is no way to ascertain whether a video has been verified by

Table 1: Global Quality Scale

Score	Description
1	Poor quality, poor flow of the site, most information missing, not at all useful for patients
2	Generally poor quality and poor flow, some information listed but many important topics missing,
3	Moderate quality, suboptimal flow, some important information is adequately discussed but oth-
4	Good quality and generally good flow, most of the relevant information is listed, but some topics
5	Excellent quality and excellent flow, very useful for patients

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authorized healthcare professionals, policymakers, or advocates "expert" in the field of the topic of interest (Parabhoi et al., 2021). Moreover, as we conducted searches at one point in time, our results may not be reproduced due to YouTube and Vimeo's nature of new videos being regularly uploaded and removed. Finally, although no language restrictions were used, we could not create search terms for all languages. Our searches captured videos that had English titles with captions when individuals spoke their local languages. Lastly, because undergraduate reviewers spanned multiple nations meant that, while providing valuable diversity of perspective in collaborative efforts, the review process was subject to subjectivity of interpretation. Assessments of the videos with the two scales were subject to variability between reviewers.

Results

Description of the Videos

Our searches yielded 62 videos (see Figure 1 for the PRISMA diagram). After assessing whether each video met the inclusion criteria, we included 14 videos (see Appendix for the list of included videos). Most videos were published by news outlets (57.2%) with the rest created by research organizations (21.4%) and civil society organizations (21.4%). Many of the videos were from African countries, but not all clearly described their geographical focus. Figure 2 depicts that most of the main characters (i.e. those whose voices were most prominently featured) were mothers (7 as PWA themselves, 14 as mothers of children with albinism). Secondary characters (i.e., people who were briefly interviewed or the subject of the interview) were predominantly children (9 PWA, 1 without albinism). Other secondary characters were healthcare professionals (3), advocates (2), and fathers (2). The intended audience was largely the public; however, three videos were aimed at educating parents of children with albinism.

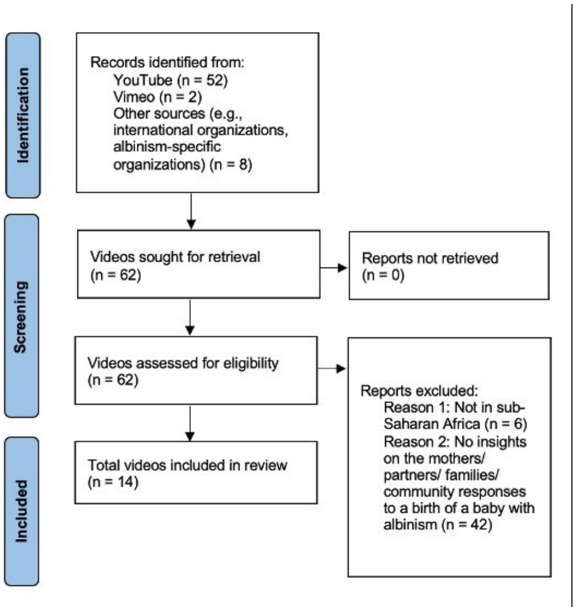

Figure 1: PRISMA Diagram

Content Analysis

In this section, content analysis on the extracted narrative data from the videos analyzed is presented, identifying themes to make meaning of how the experiences of mothers, families, communities, and HCPs are portrayed. The content analysis also identified themes for support required for mothers who give birth to a child with albinism.

Mothers' Experiences and Responses to the Birth of a Child with Albinism

Mothers in the videos described their experiences of birthing a child with albinism using their emotional responses: confusion and shock, fear and worry, anger, and acceptance. It was found that 80% of the videos showed mothers experiencing more negative than positive feelings. Initially, many mothers faced disbelief due to an unfamiliarity with albinism, leading

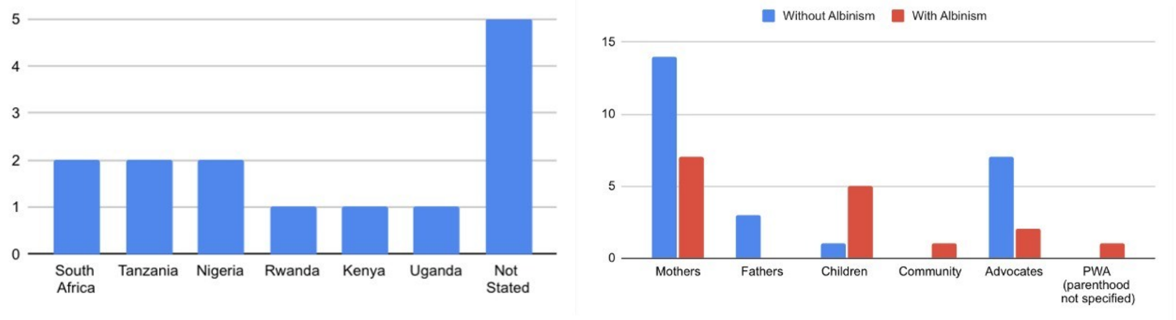

Figure 2: Country and Characters Represented

to mixed feelings about their children (Mothering & Albinism [M&A], 2022; UN Independent Expert on Albinism [UNIEA]; 2022, Journeyman Pictures, 2022). Such negative feelings, in addition to inadequate healthcare support, intensified their struggles such as the increased financial burden with women in the videos seen living in poverty. Their circumstances left them feeling isolated as they navigated the complexities of raising a PWA (Africa Albinism Network, 2022; BBC News Africa, 2019). There were, however, some mothers who accepted their children's condition from the beginning but rarely received positive responses from their community. This lack of acceptance and inclusion from the community further deepened their sense of isolation, complicating their efforts to ensure a nurturing environment for their child. HCPs were not able to provide guidance due to their limited knowledge and were also influenced by erroneous cultural beliefs (Deutsche Welle, 2022; Centre for Human Rights, 2020).

Families and Community Responses to the Birth of a Child with Albinism

Positive responses by families included acts of support (Afrimax English, 2020; BBC News Africa, 2019; Channel 4 News, 2015), acceptance (Deutsche Welle, 2022; BBC News Africa, 2019; Channel 4 News, 2015), protection (BBC News Africa, 2019; Channel 4 News, 2015), and bravery (Afrimax English, 2020). One such action was a father stating, "We love him so much, he is a blessing" when he discovered his newborn son had been born with albinism (Channel 4 News, 2015, 4:41). A father was also seen to be more involved such as attending an appointment with the genetics clinic (M&A, 2023). Not all responses of family members were positive, however, encouraging responses helped motivate PWA to face their daily struggles with renewed courage. Negative responses from family included abandonment (Afrimax English, 2021; Every Child Ministries Uganda, 2019), rejection (M&A, 2022; Afrimax English, 2021a), fathers and family falsely accusing mothers of witchcraft or infidelity (UNIEA, 2022), and expressions of shock (Afrimax English, 2022; Africa Albinism Network, 2022). Most accounts of fathers, for example, were of second-hand accounts with one mother recounting her husband questioning, "why are you birthing kids of this colour?" and stating, "then the devil entered the man and he threw me out with the boy" (M&A, 2022, 7:15). Family holds important value in many Sub-Saharan contexts and their lack of support for women increases their vulnerable status.

Moreover, the well-being of individuals is greatly affected by their community. Positive responses from community members such as visits from a religious leader to provide encouragement helped PWA and their families withstand mistreatment. A family stated the following when visited by a religious leader: "he encouraged us not to hold in anger and his frequent visits built our faith more and more" (M&A, 2022, 2:23). While positive responses occurred in the analysed videos (7%), negative responses were overwhelmingly more common (93%). These responses included stigmatization (Journeyman Pictures, 2022; Africa Albinism Network, 2022; Deutsche Welle, 2022), providing poor advice in reference to albinism (M&A, 2022; Afrimax English, 2020), hostile acts (UNIEA, 2022; Channel 4 News, 2015), ostracization (Africa Albinism Network, 2022; M&A, 2022; Afrimax English, 2021b), bullying children with albinism in school (BBC News Africa, 2019), and ridiculing PWA and their families (Afrimax English, 2021b; Afrimax English, 2020; Every Child Ministries Uganda, 2019). A Tanzanian mother stated that PWA are treated as if they are "incapable of anything and have no opinion to share with society" (M&A, 2022, 3:00). Many instances of mistreatment occurred due to misunderstandings about albinism.

Responses of Healthcare Providers to the Birth of a Child with Albinism

The responses of HCPs were found to influence the acceptance of a baby with albinism through their ability to provide information about albinism, as well as connect parents with local resources. In some instances, doctors provided genetic information regarding PWA to the mothers, and referred them to a specialist and counselling (Deutsche Welle, 2022). Chantal, a mother of a PWA, stated, "at that moment [I] had given birth, the doctors came and talked to [me] about albinos, and they told [me] that albinos were normal people, just like others, but their only difference was their skin colours" (Afrimax English, 2020, 1:30). While some HCPs were found to improve the experience of new mothers, others responded in a manner either lacking encouragement or failing to provide important referrals. One mother recounted, "I had a remark from one of the doctors who conducted the [Caesarean section] on me that 'why is this baby like this?'" (Africa Albinism Network, 2022, 22:30). When Kenyan albinism advocate Jane Waithera was born, the midwife screamed at her mother and asked, "What is that?" referring to the newborn, leaving the mother questioning the cause of her child's condition and ashamed of her newborn (Deutsche Welle, 2022, 0:20). Most mothers and PWA recounted HCPs not possessing the necessary knowledge about albinism (40%) or failing to address the issue (33%) and, as a result, were shocked and unable to support the mothers upon seeing their child for the first time. In addition, HCP could not provide adequate education or referrals (Centre for Human Rights, 2020) which are necessary to ensure

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they have the resources and information they need to raise their child such as knowing the importance of sun protection and cancer screening.

Factors Affecting Mothers and Families with Children with Albinism

Due to the unique ability of videos to provide a public platform, mothers were forthcoming to share factors that have both worsened and improved their experience of giving birth to a child with albinism. Mothers in the videos were negatively impacted by blame, accusation (UNIEA, 2022), discrimination, stigmatization, (M&A, 2022), mockery, lack of acceptance (Afrimax English, 2020), neglect, (Journeyman Pictures, 2022) and lack of educational supports (Africa Albinism Network, 2022). When the community embodied such factors, it left mothers feeling abandoned and increasing the likelihood of their children growing up in an environment lacking inclusion. Much of the mistreatment stems from the belief in myths about the etiology of albinism.

Initiatives such as awareness programs (UNIEA, 2022), education (Center for Human Rights, 2020), financial support and income-generating programs like microfinance for PWA and their families, and access to health services including skin and eye care and genetic counseling (UNIEA, 2022) supported mothers and their families affected by albinism. Educational interventions were identified to correct false beliefs such that albinism is the consequence of women sleeping with white men (UNIEA, 2022). Supporting physical needs while addressing the underlying causes of mistreatment were highlighted as priorities to protect the rights of PWA (M&A, 2022; M&A, 2023). Creating awareness programs through television, radio talks and other online media sources extends the reach of correct information and addresses the fundamental misunderstandings that lead to violence (UNIEA, 2022).

Discussion

Our findings resonate with other studies, such as mothers' experiences of shock and uncertainty upon the birth of their child (Reimer-Kirkham et al., 2024a), mothers' negative experiences attributed to the unhelpful reactions of HCPs (Taylor er al., 2021), the accusation of a mother's wrongdoing as the cause of albinism by partners and families (Kromberg, 2018), and stigma and discrimination by community members because of misinformation about albinism (Ero et al., 2021, p. 2). This paper adds to existing literature on the positive experiences of mothers and their families, highlighting factors such as awareness-raising and health education that promote the inclusion and acceptance of mothers and their children affected by albinism. Another key contribution of our study is the perspectives of fathers. In existing literature, they have almost exclusively been represented negatively with reports primarily highlighting them rejecting their children (Aborisade, 2021; Reimer-Kirkham et al., 2019) with hardly any first-hand accounts. In contrast, two videos in this study (M&A, 2022; Sgtrius, 2005), showed the father not only accepting but showing excitement at having a child with albinism and being actively involved.

A great amount of work on albinism involves written accounts whether in academic literature (Reimer-Kirkham et al., 2024b), organization and government reports (e.g., Republic of South Africa, 2023; UNGA, 2020), or news reports (e.g., Walsh, 2024). This paper brings a unique and insightful addition to the current literature on albinism because, by engaging with videos, we were able to be immersed in stories and lived environments. We observed body language, witnessed deep emotions as characters shared their stories, and saw the environments where individuals lived and how they interacted with other people present in the videos. The narratives were brought to life as participants shared their experiences in a unique way that may not be fully captured in written stories. Audiovisual sources served as a bridge to their daily life and we caught a glimpse into their "real world" and specific situations, witnessing first-hand how they continued to be resilient. In addition, the increasing use of videos in the media aids in dispelling the myths by showing the person beneath albinism, such as displaying them interacting with and supported by their community members and how they navigate the challenges in their lives.

All videos included in this analysis were accessible via public domains. As this analysis identified the importance of education for both mothers of PWA and the communities they are situated in, the public nature of the videos lends itself to widespread education. Organisations were able to feature PWA and their families while highlighting their key concerns. Educational initiatives that correct misconceptions of albinism, condemn malicious acts, and engage community stakeholders are crucial in addressing the inequities PWA face. With women accused of unfaithfulness or previously mocking a PWA, teaching about the genetic nature of the condition would address the mistreatment and accusations they encounter (Ojilere & Saleh, 2019). These interventions must engage community stakeholders such as schoolteachers, police, medical practitioners, traditional healers, and farmers as these parties influence public knowledge. Women and children affected by albinism in the videos recommended the creation of awareness programs through television and other media sources as news and media coverage are important in health promotion (UNIEA, 2022; Owusu-Addo et al., 2018).

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Furthermore, the findings revealed the need for economic security. For example, in a video from Afrimax English (2022), financial assistance was highlighted as many PWA, and their families live in poverty. The combination of living in rural areas and experiences of bullying in school leading to drop-out have resulted in PWA having limited job opportunities and often being forced to rely on agricultural occupations (Tambala-Kaliati et al., 2021). Such work exposes PWA to excessive amounts of sunlight and increases their risk for skin cancer. When PWA lack financial resources, they are unable to buy much-needed sunscreen (Tambala-Kaliati et al., 2021). Providing financial support and access to employment for PWA represents another way to support this population amidst the effects of multidimensional discrimination. For sustainable positive outcomes for PWA, it is equally important that the root causes of inequities are addressed.

From our video analysis, it is evident that the experiences of PWA, mothers, and families are not isolated to individual experience and are instead situated within the community around them (Buyco, 2023). As the communities better understand albinism and become willing to support their peers in navigating the birth and rearing of a child with albinism, these narratives can finally begin to change. All stakeholders have a role in this transformation. Whether one's area of expertise lies in nursing, videography, or human rights advocacy, all can make contributions to improve the conditions in which PWA live, work, and play.

Conclusion

Through analysing videos available to the public audience, we found that mothers of PWA and their children face mistreatment from erroneous beliefs about albinism. With mothers’ experience of raising their children so closely tied to the community around them, multimedia educational initiatives like videos will better inform both healthcare practitioners and the public about the cause of albinism. A better-informed community will, in turn, decrease blame attributed to mothers, promote better access to local resources like sunscreen, and enhance flourishing for mothers and their children. The instances in the study’s included videos where families and communities chose to support and accept the mother and their new child indicate that change can happen, and that both cultural and systemic changes such as public awareness on albinism and increased health access and funding to support the health of PWA (e.g., health education and access to sunscreen, skin cancer screening and treatments) can improve the experiences of this population that too often experience ostracization, ridicule, and acts of violence.

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