

(In)visible Stories:

Navigating Visual Participatory Research Methods among Youth with Albinism in Zambia

Visual Ethnography

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Abstract:

In most African countries, people with albinism are socially hyper-visible due to their physical differences and face multiple levels of discrimination. This paper focuses on utilizing and reflecting on two participatory visual methods in our work with children and youth with albinism during our fieldwork in Zambia. The first part provides an overview of the context of albinism in Africa to outline the research focus and introduces the field research conducted in Lusaka, Zambia. The following section outlines the methodological framework of the research, centering on application of photo-elicitation and photo-diary methods. These approaches enabled us to delve into the lived experiences of our participants, providing rich insights into their interpretations and daily realities. The paper concludes with a reflection and evaluation of these methods, emphasizing their significance in field application and data acquisition, especially when engaging with a marginalized and vulnerable population group.

Keywords:

Albinism; Zambia; Photo-diary; Photo-elicitation; Participatory research.

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1 The formerly common term “albino” is considered derogatory because it implies an inherent connection between the condition and the person, ultimately defining the person’s nature. To overcome the negative connotations, an alternative term “person with albinism” has been established. Steyn (2022) notes that “person with albinism” reflects a linguistic and semantic shift as it puts the person before the condition of albinism, reducing the pejorative character of the word “albino”.

2 This also echoes in the term *Money*, which is one of the derogatory terms that some people in Zambia use to refer to a person with albinism.

3 The reason is twofold. First, the perpetrator or accomplice is most often a member of the family of the attacked, which usually results in the silence of the family. Secondly, the cognitive framework of understanding magic as a real part of everyday life may lead to a fear of reprisal, which limits investigations (especially in rural areas).

Introduction

Due to a lack of public education and medical knowledge, alongside prevailing cultural beliefs about albinism, people with albinism¹ often face social stigma, discrimination, and exclusion from both family and community. This article is based on a qualitative study centered around children and youth with albinism in the urban settings of Zambia, a context often overlooked in mainstream research. The primary aim of this article is to reflect on the application and effectiveness of visual participatory methods in engaging with marginalized groups and sensitive topics.

After initially outlining our research focus and approximating the topic, we will demonstrate the benefits of incorporating visually-based participatory methods, using our study as a specific example. We will also evaluate the success of our endeavor. Throughout this process, we will illustrate our statements with data from our participants’ photo-diaries, which serve as a key source of data for our research. Finally, we will discuss the potential consequences of incorporating participatory visual methods into our research design and how they can empower our participants. We believe that integrating visual approaches into research designs can offer numerous benefits and significantly enrich the resulting data, particularly for topics that are challenging to address due to their sensitive nature.

Albinism in Zambia

Albinism encompasses a range of congenital disorders caused by a genetic mutation, primarily characterized by reduced melanin production, and associated health issues. People with albinism commonly face visual impairments and a heightened risk of skin cancer, a concern that is especially acute in Southern Africa due to environmental factors. These health challenges, coupled with limited medical understanding and deep-rooted cultural beliefs about albinism, significantly impede the social and economic participation of affected individuals. In many African regions, cultural beliefs, often intertwined with magic, mythology, the supernatural, or religious interpretations, predominantly shape perceptions of albinism, overshadowing biomedical explanations (Steyn 2022).

The most common beliefs about albinism in Zambia include the assumption of supernatural properties of various body parts of people with albinism, the birth of a child with albinism as a punishment based on a woman’s infidelity or as a family curse, the contagiousness of albinism or the disappearance of the bodies of people with albinism after their death. These or similar beliefs are also commonly prevalent in other African countries that frame albinism in a similar perspective (Lund 2000, Kromberg 2018, Baker et al. 2010, Kimbassa 2016). Those ideas, especially the belief that magical powers can be extracted from body parts to bring money and prosperity, then lead to various forms of stigmatization, violence, ritual killing, mutilation and human parts trafficking.² This phenomenon, which has received international media attention in recent years, is particularly well known in the context of Tanzania, which has been a hotspot for these attacks for many years (Brocco 2016, Dave-Odigie 2010). In response to the challenges faced by people with albinism, the Tanzanian government has implemented legislative measures and policies aimed at their protection, which have led to a decrease in attacks. However, these attacks often stem from deep-seated beliefs and practices associated with magic and the supernatural, which fuel the demand for albino body parts. As a result, smuggling networks have partially shifted their operations to neighboring countries, including Zambia. Zambia remains among the countries where people with albinism are not sufficiently protected legislatively or legally, as assaults or court cases related to albinism are frequently unresolved or not thoroughly investigated by the police.³

Deeply rooted cultural-aetiological framing of albinism profoundly affects the social and economic participation of people with albinism, access to health care and education (Clarke and Beale 2018). Children with albinism struggle to graduate from primary and secondary schools because of their visual impair-

ment deficit that is not properly accommodated or due to common occurrence of bullying. This further disadvantage them in the labor market, where their opportunities are already constrained by the necessity to limit sun exposure due to health risks, which often leads to their economic marginalization and poverty.

Women, and particularly mothers of children with albinism, confront additional layers of social stigma and exclusion, both within their families and the wider community. The pervasive belief that a child with albinism is the result of infidelity or a curse often leads to the mother and child being rejected by their partner.⁴ Single mothers then face an additional economic disadvantage and must often rely on the support of their family. Women with albinism also face sexual abuse, because despite the primordial albino-phobia causing aversion to contact with a person with albinism, one of the more contemporary beliefs is that sex with a person with albinism will cure AIDS (Steyn 2022).

With the growing public awareness of the challenges faced by people with albinism, numerous NGOs, both local and international, have been established. In Zambia, organizations like the Albinism Foundation of Zambia and Zambia Albinism Matters Organization, with whom we collaborated during our research, are actively advocating for and assisting individuals with albinism. Their efforts are largely focused on public education and engaging the community, particularly mothers of children with albinism, through various awareness programs. These NGOs often collaborate with government agencies, including the police and hospitals, to reach families where albinism is present. In addition to advocating for the rights of people with albinism, these NGOs play a crucial role in distributing sunscreens, a vital but scarce and expensive commodity in Zambia. Due to these constraints, these organizations often rely heavily on funding from foreign donors to sustain their operations.⁵

Research

Our study focused on exploring the daily experiences of children and youth with albinism, examining their internal perception and interpretation of their “sameness” and “otherness” within various social contexts (including family, neighborhood, school, church etc.). Emphasizing the emic perspective, we primarily employed classical and visual ethnographic approaches. We employed two participatory visual methods, namely photo-elicitation and photo-diary, which will be elaborated upon later. Our access to the field was facilitated through contacts we gained during prior fieldwork in Lusaka, especially through cooperation with local NGO. Due to concerns about potential threats or attacks, it is very difficult to approach people with albinism (and children especially) without prior contact. Establishing a connection with a longstanding NGO operating in that area was crucial for us to carry out the research in this scope. Our overall research sample consisted of ten children with albinism aged between 6 and 17 years, with six of them actively engaging in the photo-diary activity. All participants were enrolled in a standard school⁶ within their local community and resided mainly with their matri-lateral close relatives. From the socio-economic point of view, it mostly concerned low-income families, residing in poverty-stricken compounds⁷, namely George, Kabanana and Chunga compounds.

Ethics

Working with vulnerable populations such as people with albinism or children and youth necessitates careful considerations to safeguard their rights, dignity and well-being. In accordance with the ethical principles of anthropologic work, we have anonymized all participants. Children’s participation in the research-related program was voluntary, and we obtained informed consent from parents. The document was in English, which is one of the official languages of Zambia, but due to the illiteracy of some parents, we also translated its content through a local interpreter who accompanied us. The families’ involvement was not compensated financially. However, during home visits, in consultation with the NGO representative, we provided food donations as a gesture of appreciation.

4 Mothers often frame the birth of a child with albinism in religious terms, seeing the child as a gift from God, no different from others except for skin color. This concept became particularly clear in the case of one of our participants, whose name translated meant *miracle*.

5 However, it is observed that certain organizations exploit the financial assistance intended for supporting individuals with albinism in Zambia. Initially, there was noticeable wariness or suspicion among certain families, which was rooted in their past negative experiences with other organizations or researchers. These groups had promised to help in exchange for their participation but ended up taking advantage of them instead.

6 With the word standard we refer to governmental or private schools that are not focusing on children with disabilities, as some children with albinism attend specialized schools due to their visual impairment.

7 A ‘compound’ refers to a densely populated area consisting of small homes or informal dwellings, and most of Lusaka is made up of such compounds. These areas are characterized by limited access to amenities, services, and infrastructure.

Methodology

In our research, we employed a combination of classical and visual ethnography design and phenomenological design allowing us to deeply understand the emic perspective of children with albinism regarding their own sense of otherness and sameness. To achieve this objective, we employed various research techniques such as photo-elicitation, participant-generated photo-diaries followed by unstructured interviews over visual material, children's drawings, semi-structured interviews with mothers, and participatory observation.

Choice of the research design was based on a premise of wider universality of visual language, which, to a large extent, is exempt from the need for knowledge of the local language of the participants. Apart from more traditional verbally based methods, we decided to incorporate into our research as many visually based methodological approaches as possible. As we confirmed later on during the process of data collection, solely spoken communication with the children due to the language barrier would be nearly impossible and would certainly cause limited outcome of the field work. Engaging with young people by the means of image proved to be a fruitful approach in many previous occurrences, as it encourages a form of communication that is often more innate and natural for them. It is no coincidence that visually based research was widely developed in the field of child psychology in order to let them express suppressed feelings that are difficult to articulate verbally with the help of drawings (Literat 2013). Finally, an important factor to consider is the interest in the cameras themselves. The technological equipment functioned as a bit of an alien element in the environment which naturally raised curiosity of the locals, kids especially. (Fig. 1, 2 & 3)



Image 1 Carrying around cameras and printed images not only raised the interest of children with albinism but also attracted the attention of children passing by in the compounds (Source: Photo documentation made by the research team.)



Image 2 Source: Photo documentation made by the research team.



Image 3 Source: Photo documentation made by the research team.

Photo-elicitation

Douglas Harper (2002) states that the difference between conversations incorporating images and exclusively verbal conversations lies in the way in which people respond to these two forms of symbolic representation. This has a physical basis: the parts of the brain that process visual information are developmentally older than those that process verbal information. Consequently, images tend to evoke more profound elements of human consciousness than words. Communication based only on words engages less of the brain's capacity compared to when the brain interprets both pictures and words. This fundamental understanding is a key reason for our decision to utilize photo-elicitation interviews in our research.

The core element of photo-elicitation is not simply that the interview process elicits more information, but rather that it invokes a different, novel type of information, which might be otherwise missed out. Alexander Freund and Alistair Thomson (2011: 1) argue that photographs can help narrators express alternative life stories and „visual life storytelling may uncover or generate conflicted feelings and understandings of one's life choices and experiences“ compared to life stories which may surface in traditional storytelling. In our case, this aspect was also widely supported by the nature of the interpreted data itself – for our interviews we chose to work with visual diaries created by our participants themselves. (Fig. 4)



Image 4 Throughout the article to demonstrate our points we will be using photographs taken in the framework of several photo-diaries. Nevertheless, we will concentrate extensively on photographs within one particular diary, which we found extremely expressive and complex. For example, in this particular picture, the author (a 14-year-old boy who we will be calling Max) photographed the dumped trash outside his house. As he explained later, he did so because the omnipresent trash around the compounds is a source of many concerns for him (as for example cholera outbreaks are not an exceptional phenomenon in Lusaka compounds). (Source: Max's photo-diary.)

Our selected approach falls under the umbrella of participatory-based (also referred to as collaborative) visual methods (Margolis and Pauwels 2011) which are unified by the fundamental belief that those who are subjected to the research should play a more significant role in the process of generating data and consequently be also more involved in the resulting form of narration provided by the research than they used to be in the past (Mannay 2016). Such methodologies therefore significantly support incorporating emic perspective into the research process and its outcomes. Another important aspect of including visual participatory methods into research is their ability to serve as platforms for increasing visibility of marginalized social and ethnic groups. Since invisibility of people with albinism was also one of the main topics our research project dealt with, the possibility of improving lives of our participants, raising awareness about them in their community and empowering often very disadvantaged children seemed like a desirable (even though originally not the primary one) effect of our field work.

Photo-diary

Planning the most fitting research approach, we had to carefully take into account the age of our participants. Based on previous research of literature, we made a decision to work with different age groups by specific means. Younger kids were asked to create drawings depicting significant points in their lives which we believed could help us reveal their understanding of their social reality, their coping strategies and relationships within the community. We discussed these drawings later with the help of a translator during unstructured interviews and compared them to drawings of classmates without albinism of the same age with similar social backgrounds.

For kids older than twelve years we devised a more complex task: they were asked to work with small digital cameras and create a photo-diary representing both their typical day and their Sunday. We instructed them to capture 50 images reflecting the key facets of their daily lives, encompassing objects, people, and various situations, including both positive and negative experiences. They were instructed to photograph anything which makes them happy, worried, bored, annoyed or in any other way makes them feel strong about something (that is any daily elements that elicited strong emotions). (Fig. 5)



Image 5 Screenshot of complete set of thumbnails of one of the diaries (Source: Max's photo-diary.)

The underlying premise of this approach is that significant patterns of the participant's culture - norms, values, expectations, etc. (Fig. 6, 7 & 8) - can be expressed in the images that participants make (both in what they depict and how things are depicted) and thus revealed to researchers and other participants (Pauwels 2015).



Image 6 Source: Max's photo-diary.

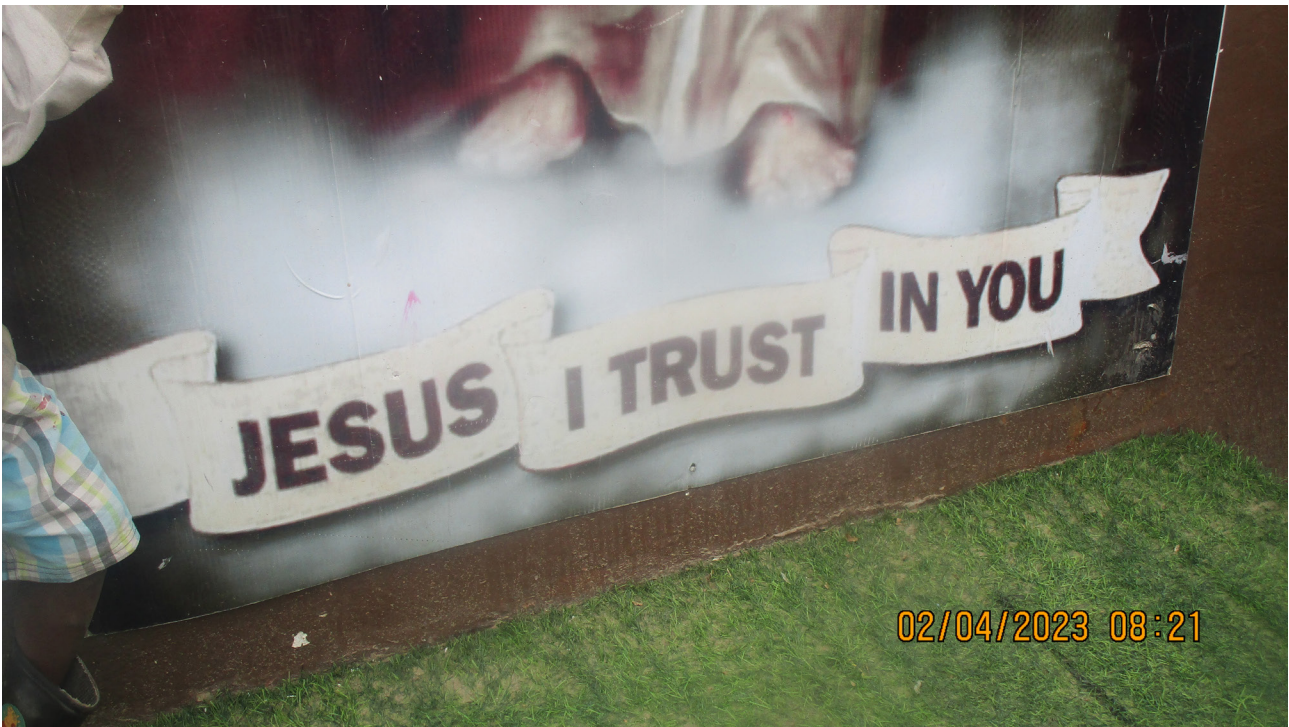


Image 7 Source: Max's photo-diary.



Image 8 Figures 6, 7 and 8 from Max’s diary were supposed to represent his time spent with family at church on Sunday, but also his deeper relation to Christianity. In the interview, he describes his sense of connection to Jesus. One of the striking points he mentioned was that he felt similar to him, because on the posters around compounds he was depicted as white (therefore similar to Max).

Auto-driven photo-elicitation

8 This was also the case when working with some of the drawings. One of the younger girls drew an image of a complete family, but later, in a photo-eliciting interview, it was revealed that this was just her fantasy and the picture did not depict her actual family situation at all.

There are several layers to be considered about the outcoming images we would like to underline here. First layer is recognizing the primary object intentionally depicted in the image. Researchers can easily access the inventory of taken images and approach them as a collage of impressions from the field – social reality surrounding the participant. In our research, this part was not so hard to grasp, since we managed to make an interview with all the children involved in the research and they explained all the content to us “first hand” (Fig 9, 10, 11 & 12), which is not always automatically so easy when working with previously created images not for the intention of the research whose author is not available to offer explanations to the researcher.⁸



Image 9 Source: Max’s photo-diary.



Image 10 While many of the depicted objects were self-explanatory (for example, most of the children recorded meal preparation in some form - Figure 9, others could not be correctly interpreted without explanations. Initially, when looking at Figure 10, we thought we were seeing another record of the trash problem. However, Max corrected our assumptions. The bottle in the picture actually served as a makeshift football, as the kids couldn't afford a real one. (Source: Max's photo-diary.)



Image 11 Source: Max's photo-diary.



Image 12 Another example of potential misinterpretation can be seen in photographs 11 and 12. We originally assumed that they depicted activities Max enjoys with his friends. However, this wasn't the case. The boys in these photos neglect Max due to his medical condition and refuse to spend time with him. According to Max, the pictures represent his feelings of rejection and explain why he spends a lot of time with much younger children, who are friends with his younger brother (Source: Max's photo-diary).

Another layer, perhaps even more significant, is how the participant relates to the content of the photograph and refers to it during the elicitation interview. A vital component of our elicitation process was observing the manner in which the kids presented and described taken images to us, the observers. Despite instructions to capture various aspects of their everyday lives (both pleasant and unpleasant), some of them chose to skip some of the slides and focused solely on positive images during the interviews. This selective representation allowed them to exert greater control over their storytelling, thus shaping the narrative about their personal identities. Therefore, they became more powerful agents in constructing the storytelling and shaping the narrative. If they didn't want to talk about something, they simply skipped it, or even didn't take the picture of it in the first place and hid the fact that it's part of their lives before us.

While the diary method's potential for selective representation might initially seem like a drawback, we on the contrary view it as an auxiliary tool which helps us identify crucial sensitive areas of everyday reality for our participants. Our approach was to fill in these gaps during the accompanying interviews. Recognizing a participant's intentional omission of certain aspects enabled us to approach these topics with greater sensitivity in later discussions. (Fig. 13) Some scholars emphasize that the absence of certain depictions can be as revealing, if not more so, than what is explicitly shown when constructing the narrative, because narrators usually tend to present an ideal image of themselves or their family (Erkonan 2016). This perspective proved its validity also in our research, as these omissions often provided critical insights into the participant's experiences and viewpoints.



Image 13 For example, one 14-year-old girl, who we will call Elena, repeatedly photographed her aunt, while there wasn't a single picture of her mother. This was quite distinctive compared to the diaries of the other children. When we inquired why she chose not to include her mother, it was revealed that her mother was often absent from home, a sensitive topic for the girl as she frequently missed her support. Consequently, she often sought help from her aunt. (Source: Elena's photo-diary.)

Placing the participant in the role of the creator of their own story, as opposed to merely being the subject of inquiry, fundamentally alters the dynamics of the ongoing interview. Participant takes on the role of an expert, who is explaining, managing the conversation.

When commenting on images, interviewees tend to feel much less as if they are talking about things they should not be talking about. Instead, they feel as if they are simply explaining things that have already been captured by the recording (Pauwels 2015: 98)

While this approach admittedly reduced our control over the material discussed to significant extent, the benefit of overcoming the language barrier thanks to participant-created photographs was unquestionable and helped us to an immeasurable extent.

Evaluation

In applying the above methods in the field, we identified a number of advantages and encountered a number of challenges during the fieldwork. Leading benefits included establishing trust and engagement, minimizing discomfort and enabling participants to co-produce data. The primary challenges encompassed technical issues, time and organizational requirements, age-related differences in effectiveness and security considerations.

Establishing trust and engagement

We found that photo-elicitation played a significant role in establishing trusting relationships with participants who were initially closed, quiet, soft-spoken, or distrustful. Introducing new technology and leveraging their interest in photography sparked engagement and enthusiasm, creating a more open research environment. (Fig. 14 & 15)



Image 14 Source: Photo documentation made by the research team.



Image 15 Source: "tryout" for making the photo-diary, documented by Max.

The joint activities preceding interviews over the recorded material enabled us to develop a cooperative relationship with the children in a relatively short period of time. This connection significantly eased communication regarding the more challenging topics that surfaced during the interviews.

Minimizing discomfort

Discussing sensitive topics like difference, discrimination or stigma can evoke uncomfortable feelings of shyness or shame in participants. The inclusion of photographs enriched the context of the discussed topics, allowing for their natural development in relation to the visual content. Photo-elicitation became an alternative communication method, enabling participants to express their experiences or concerns through photographs. (Fig. 16) This approach offered a way to bypass direct verbal confrontation, providing a more comfortable means of expression. Despite using an interpreter, the use of photographs during interviews enabled us to overcome the language barrier to a certain extent.



Image 16 We encountered several situations where finding the most sensitive way to address difficult topics, which significantly impacted the quality of life of our child participants, was challenging. Therefore, we were very grateful when these issues were explicitly mentioned in the diaries, allowing the children to voluntarily open up about these topics. In one instance, Max took a striking photograph of his flooded house, which forced him to leave and live with his large family in a much more crowded space. (Source: Max's photo-diary.)

Participants as co-producers of data

Compared to the methods of classical ethnography, where there are limited possibilities for participants to become active agents in the process of data creation, using methods of photo-diary and photo-elicitation enabled our participants to actively contribute to discussed topics. The process of capturing and selecting images as a foundation for the interview allowed them to introspect on their perspective and experiences. For us, it opened up new meanings and topics that may otherwise have remained hidden if we had used a traditional interview. An important element was the criteria of importance/unimportance, which allowed us to understand the hidden meanings of the photographs and helped us to understand even minor nuances. It also provided a sense of autonomy, as participants decided on the significance of a given photo during interviews, which enabled us to pursue substantial topics in depth.

Technical issues

Navigating the technical aspects of our methods emerged as a significant challenge. We carefully selected photographic equipment that could accommodate the visual impairment of children with albinism. Opting for small digital cameras with displays allowed participants to review their captured material visually. However, the number of available cameras was limited, so we had to carefully plan ahead. Managing rapid battery drainage in hot climates posed additional hurdles, prompting us to ensure consistent charging

and provide spare batteries to mitigate potential technical disruptions for the participants. Furthermore, the research period was affected by daily power outages, necessitating strategic adjustment to our approach.

Time and organizational requirements

Employing the photo-diary method revealed itself as both time-consuming and organizationally taxing. This entailed efforts in training on how to use the photcamera, offering technical assistance, ensuring safety measures, and overcoming geographical distances between participants residing in various compounds across Lusaka for camera distribution, collection or interview. Coordinating interview schedules with parents proved challenging, as our presence in their home would disrupt the documented daily aspects captured by their children during the photo-diary. Additionally, navigating frequent last-minute changes or delays from parents demanded flexibility and prompt adaptability on our part.

Age-related differences in effectiveness

During the training workshop, we observed varying levels of effectiveness in handling the camera and understanding the assignment among different age groups. The level of visual impairment also influenced participants' capabilities. Younger individuals required additional time and guidance to comprehend and engage effectively with the method. Older participants swiftly grasped the technical aspect and assignment, demonstrating independence in their work. In response to these observations, we adapted our approach by limiting the participation of younger children to the drawing method, which was less engaging for the majority of older participants.

Security considerations

The implementation of the photo-diary method within poverty-stricken compounds inherently introduced several potential risks and ethical dilemmas. Primarily focused on ensuring participant safety, we remained vigilant regarding the potential threats of theft, as well as physical or verbal violence directed at our participants. To address these concerns, discussions were held with both NGO representatives and families, leading to the implementation of various security measures. Initially, we provided the children with tags containing project information and contact details for both our team and the NGO staff. (Fig. 17) However, the visibility of these tags inadvertently drew unwanted attention to the children, prompting us to adjust our strategy by concealing the tags. Moreover, we arranged the possibility of being accompanied by a local guide during their photoshoots, enhancing their safety within the environment. (Fig. 18)



Image 17 Source: Max's photo-diary.



Image 18 This photograph captures the attention of bystanders drawn to Max's camera, as well as the presence of a local guide standing in the background. The guide accompanied Max for this very reason. (Source: Max's photo-diary.)

Photovoice and empowerment through photography

The use of visual ethnographic methods in our fieldwork presented opportunities for participants to engage in related non-research activities. A notable example was the preparation and implementation of a local photography exhibition (Fig. 19, 20 & 21) at their school promoting social inclusion within their community. This involvement empowered participants by allowing them to share their stories, experiences, and emotions through photography, a medium that transcends social barriers, which connects our approach to a method of photovoice.



Image 19 Source: Photo documentation made by the research team.



Image 20 Source: Photo documentation made by the research team.



Image 21 Source: Photo documentation made by the research team.

Photovoice is understood as a process in which grassroots communities are asked to document their lived experience through photos and discuss these photos, with the aims of identifying and representing their community, promoting dialogue, encouraging actions, and potentially influencing decision making on the policy level (Wang and Hannes 2020: 2).

As destigmatization was one of the accompanying objectives of our involvement in the field, we accordingly tailored the ways of engagement of the children during the accompanying research activities and we now consider them to be the most empowering aspect of our methodology. First such facet is the authentic authorship of the photographs. The possibility to become an active visual narrator, who has the power to choose what is important and what is not and therefore what will be told and in what specific manner, relieves marginalized people from the objectification and eventual imprecise representation. Although our research team included two photographers producing social documentary images and portraits of the children with albinism, photographs taken by the children themselves are particularly valuable in this context. Offering a space and means for imagination development and creativity is itself “centralized as a vehicle of empowerment” (Mannay 2015: 46). (Fig. 22)



Image 22 To express his longing for an often-missing father and desire to fulfill the idea of “complete family”, this boy, in our opinion quite creatively, chose to photograph himself by the wall “holding hands” with his imagined relatives. (Source: Max’s photo-diary.)

For many of the participating children the amount of attention from adults was notably important, a level of attention we believe they are not typically accustomed to. It’s important to clarify that this observation was not specific to the children with albinism but applied to all the children we encountered in the compounds. This was evident in the case of one of the older girls, who was eager to share her passions and future plans with us and greatly appreciated our interest in them.

Another aspect of our intervention was the heightened effect on social visibility of people with albinism in their environment, which is otherwise usu-

ally indifferent or even hostile towards them. Both the children's involvement in the prepared exhibition, our interest in their situation and active presence during our fieldwork in the area, where we focused on addressing the discrimination against people with albinism and their living conditions, sparked interest and hopefully heightened the awareness of local residents.

Finally, an important level of empowerment to consider is the underlying motive of raising awareness about people with albinism on an international level. Since the translocal dissemination of the collected data lies fully in the hands of the research team, the possibility of achieving this objective is closely dependent on its activities, awareness of the sensitivity of the topic and its precise presentation to the public. Dawn Mannay (2016) warns against *journalistic reductionism* which can come out as a result of power imbalance between marginalized people and those leading the research, and which can often voice over the perspectives of marginalized communities. This risk is imminently present also in many outputs of our research. Since a significant part of our fieldwork consisted of creating social-photographic documentaries, the children with albinism were constantly exposed to the risk of objectification and exoticization if we were to proceed recklessly. Presenting our data far from the narrators with them having no power over the narratives passed on to the foreign public creates an unbalanced power dynamic which strips the main actors of the control over their outer representation. We as researchers have to take this disbalance into consideration with much caution when sharing the narratives and representations manifesting from our outputs. For example, part of our research intention included organizing an exhibition at a gallery, showcasing staged portraits of our participants from the field research. To avoid their objectification due to their distinctive appearance, we complemented these with more natural depictions from their daily lives, along with extensive captions and explanations of our research activities. To balance the perspectives, we also presented one of the photo-diaries accompanied by explanatory context.

Conclusion

Enriching classical ethnographic methods with participatory-based visual methodologies proved to be a valid and fruitful strategy in our research. Given the sensitivity of the topic of albinism, the characteristics of our participant sample, the research objectives, and the limited duration of fieldwork in a specific environment, visual-based approaches emerged as a prolific source of data. These methods demonstrated their ability to overcome many obstacles inherent in field research, such as language barriers and challenges in capturing the attention of younger participants. All the techniques used complemented each other effectively.

The main methods discussed in this article, namely photo-diaries and auto-driven photo-elicitation, also presented some challenges worth mentioning. Working with a limited number of photographic equipment, particularly in Zambia's hot climate, required constant attention to the condition of their batteries, especially regarding charging. Careful management was essential in delivering and picking up cameras, ensuring each participant had two full days with them to maintain the integrity of the task framework. These logistical considerations demanded more attention than we initially anticipated.

The chosen methodology transformed the traditional dynamics between researcher and participant. By delegating the responsibility for data production to the participants, they became involved in the emerging narrative and redefined as active authors. Thus, participatory methods enabled the democratization of data, allowing participants to become co-producers of knowledge and to some extent bridge the imbalance of the researcher-participant positions. The use of cameras and photographs opened avenues for establishing open communication and sparked the interest of young research participants, who enjoyed working with technology not normally accessible

to them. This enjoyment facilitated trust and engagement, enhancing the participants' willingness to discuss freely, even on sensitive topics. Building on these points, the emerging atmosphere during our interactions encouraged openness. This allowed us to gain a deeper understanding of the personal perceptions and experiences of our participants born with albinism, offering more nuanced insights into their viewpoints. The methods discussed significantly supported incorporating an emic perspective into our research outcomes. Furthermore, the utilization of participatory methods in visual ethnography provides a more comprehensive and complex perspective on data compared to more traditional, classical approaches.

A final point to note is the empowering aspect of participatory-based methods, which are intrinsically linked to giving a voice to marginalized groups and serve as a platform for promoting their voice and inclusion in the local community. Our research activities aimed to enhance the perception of people with albinism at both local and international levels. Raising awareness of the daily challenges but also aspirations of youth with albinism became an important part of our research. The visual methodologies discussed in this article have demonstrated their exceptional capacity to contribute to achieving this goal.

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