



# “Why Always me?”: Childhood Experiences of Family Violence and Prejudicial Treatment against People Living with Albinism in Nigeria

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## Abstract

In an attempt to address the paucity of research examining the childhood experience of people living with albinism within family context, the present study explored family-based violence and prejudicial treatments against children born with albinism in Nigeria. In addition, issues that traumatized children with albinism (CWA) within their family setting, and the coping strategies they found effective were identified. The research was located within an interpretive qualitative paradigm and framed within the theories of ‘othering,’ self-esteem, and family system. Interviews were conducted with 62 adults living with albinism who were raised in family settings. The prejudicial treatments and family-based violent behaviors experienced by participants were explored, and a thematic analysis of the narratives was carried out. Findings confirm the existence of family violence and prejudice regarding albinism. Prejudices on albinism were found to result in parents denying CWA of educational and vocational sponsorship, cordial family relationship, social interactions and attendance of social events. Family members’ perceptions of CWA were reportedly influenced by social and religious inclinations. Families were found not to be only violent with CWA but also facilitating institutional violence by religious organizations. Participants expressed developing emotional problems like paranoia, anger, depression, feelings of powerlessness, and low self-esteem, while they utilized varieties of emotion-oriented coping strategies during their childhood experiences. CWA are subjected to prejudice and violence within their families that are unique and deserving of research and policy interventions. Therefore, family-based orientations, screening for family violence, religious and social groups’ support for people living with albinism (PWA) were suggested.

**Keywords** Albinism · Children living with albinism · Prejudice · Siblings · Violence

People living with albinism (PWA), which is an inherited condition from birth resulting from lack of melanin pigment and leading to changes in the color of the skin, hair and eyes, are faced with challenging lives (Taylor et al. 2019). In particular, children with albinism (CWA) have been reported to face greater discrimination and challenges than others (Franklin et al. 2018; Reimer-Kirkham et al. 2019). These discriminations are reported to be both at the institutional level, evinced by non-provision of learning aids to assist with their visual impairment (Human Rights Watch 2019; Nebre 2018), and at the individual level, as shown with teachers and staff that avoid CWA based on the myth that albinism is a

contagious condition (Lund 2005). Although, controversies have trailed the disability status of PWA because they are usually as healthy as the rest of population, they can be classified as disabled because of the associated visual impairment (Phatoli et al. 2015).

In some African communities, it is considered a misfortune to give birth to albinos; therefore, attempts are made to kill them at birth or banish them from the community (Benyah 2017; Braathen and Ingstad 2006; Cruz-Inigo et al. 2011; Nebre 2018; Reimer-Kirkham et al. 2019). Whilst there is a growing body of literature regarding discrimination and violent treatment of people with albinism at community-based level and, specifically, in the educational, health and employment sectors, there is little research on the lived experiences of children with albinism at the family level.

African body of literature on albinism has reported the pervasiveness and systemic discrimination, violence and social hostilities meted to CWA based on their conditions

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(Taylor et al. 2019). In some of these societies, CWA are given demeaning names, derogatory remarks and social tags such as *inkawu* (monkey) or *isishawa* (a curse) in South Africa (Independent News 2019), *gesoshi* (an incomplete being) in Ghana, *nguruwe* (pig) or *zeru* (ghost) in Tanzania (Cruz-Inigo et al. 2011), *sope* (which suggests that they are inhabited by evil spirits) in Zimbabwe (Simona 2004). Indeed, these studies, which present evidences of community-based prejudice and discrimination against PWA, need to be complemented with studies on their family-based experiences. The lacuna on family-based experiences of PWA may have led to the general belief that the tangible threats that PWAs are exposed to are society-based. Consequently, most governments' policies, legislative interventions and support systems are focused on addressing discrimination and stigmatization within the larger African community level.

Nigeria, with an estimated figure of over six million people living with albinism, is noted to have the highest population of PWA in the world (National Policy on Albinism 2012). In spite of the high number of PWA, research on the lived experiences of albinos has been few and far between. Therefore, it is important to conduct studies examining the childhood experiences of PWA that may be exposed to family-based discrimination and targeted violence within their family due to their disability status. Essentially, this study explored the childhood experiences of PWAs as regards their perception of domestic or family-based violence against them within the context of their disability, identifying issues that traumatized them, and the coping strategies they found effective.

## Theoretical Background: 'Othering' and Family-Based Violence against People with Albinism

In the twenty-first century, the concept of 'othering' has been identified as a significant feature in discussions surrounding global conflict. In a world that is beset by seemingly intractable and overwhelming impediments, almost every national, regional and global conflict is associated with various dimensions of group-based differences. Othering has been affirmed to undergird territorial disputes, military conflicts, and sectarian violence (Powell and Menendian 2018). In this study, the theory of othering is being extended to explain the prejudice, discrimination and violent treatment of children with albinism by their parents, siblings and significant others on their family setting in Nigeria. The sociological development of the theory of 'othering' was informed by the need to describe the processes by which people who are different tend to be perceived as increasingly alien and distanced (Cromer 2001).

According to Powell and Menendian (2018), othering is a "set of dynamics, processes and structures that engender marginality and persistent inequality across any of the full range

of human differences based on group identities" (p.15). There are different dimensions of othering, which include religion, sex, race, ethnicity, socioeconomic status (class), disability, sexual orientation, and skin tone. The alienation and distancing leads to the emergence of suspicion and a dividing wall of hostility between the *insider* and *outsider*, with the perception of those considered to be on the outside as 'others' and less desirable than 'insiders' (Cromer 2001). Although, albinism can be found in all parts of the world, however, it becomes more startling when it occurs among the dark-skinned people. This partly explains the gravity of 'othering' that PWA are subjected to within the African continent. Studies have affirmed that people without albinism in sub-Saharan Africa engage in the 'othering' of PWA, perceiving them as *outsiders* within the black African communities (Braathen and Ingstad 2006; Cruz-Inigo et al. 2011; Reimer-Kirkham et al. 2019). Therefore, this may extend to the family within Nigerian social setting, where children with albinism may suffer some forms of prejudice and violence from their parents and siblings as attitude indicative of rejection.

Literature on social discrimination of people with albinism have described the othering of PWA as a factor that impact on their social identity, their perception of society and self-esteem (Braathen and Ingstad 2006; Simona 2004). Erving Goffman (1963) came up with a widely recognized social theory that explained the relationship between disease and stigma. He described stigma as '...an attribute that is deeply discrediting, and is socially constructed on the basis of what the society regards as being different or deviant' (p. 3) The social perception of albinism as a disease, disability and difference, which leads to social stigmatization, may also impact on the ways that families perceive their members that are born with albinism. According to Benyah (2017), it is considered a misfortune to give birth to albinos in some Ghanaian communities, and hence, attempts are made by the parents to kill the baby at birth.

The effect of othering on PWA has been identified as a strong factor that may impact on their social identity and self-esteem as members of their family and society (Benyah 2017; Cruz-Inigo et al. 2011; Human Rights Watch 2019). Samuels (1977), in his self-esteem theory, stressed the need for individuals to have positive self-esteem, which is facilitated by the approval they receive from others as opposed to negative self-esteem that is caused by disapproval. The basic assumption of the theory is that individuals feel the need to enhance their self-evaluation and to increase, maintain, or confirm their feelings of worth. Therefore, the effect of othering on PWA will lead to negative self-esteem, and if they experience such othering in their families in the form of discrimination, their feelings of self-worth may be significantly affected.

In support of the self-esteem theoretical position, the family system theory underscores the importance of family as an

emotional unit that affects the thoughts, feelings and actions of members (Kerr 2000). The theory posits further that people solicit each other's attention, approval, and support and react to each other's needs, expectations, and upsets. Therefore, the condition of 'othering' in the family will deprive marginalized members, make them feel distant and disconnected from their families. According to Deal (2007), the effect of the stigma is associated with attitudes and beliefs that result in PWA feeling devalued or insecure. Deal affirmed that aversive disablism – which has to do with discriminatory, abusive or oppressive behavior – arises when non-albinos hold the belief that PWA are inferior to them.

The theory of othering and other theoretical positions presented in this section offer theoretical background for the exploratory study of the differential treatments, prejudice, discrimination and violence against CWA based on their medical and skin conditions. Although, these theories have been adopted in similar studies on disability, there is a paucity of research focusing on the narratives of PWA in respect of their childhood. Aside from covering the lacuna in the literature and theoretical perspectives on 'othering,' the current study will advance the theory and knowledge on the vulnerability of children with disability to family-based violence.

### Childhood Disability and the Family

Research on the ways that families adjust to disabled family members has been developed since 1950s and sustained till the present time (Cohen and Mosek 2019; Seligman 1999). Early studies affirmed that family members were thought to be devastated by childhood disability (McCabe 2007; Neely-Barnes and Dia 2008). References were made to such children as being 'defective,' a term that implies that they have severe and immutable deficiencies that caused profound distress to the family system (Seligman 1999).

However, based on reports and research mostly conducted in the Western countries, in contemporary times, children with disabilities and their families basically function well (Cohen and Mosek 2019). This functioning has been largely attributed to the availability of medical and social support provisions to children with disability and their parents (Mas et al. 2019). On the other hand, studies and reports about childhood disability and the family in Africa have rather focused on the challenges faced by the family in meeting the needs of children with disability, largely as a result of non or inadequate provisions of medical and social support systems to meet their special needs (Chukwu et al. 2019; Mas et al. 2019; Onyedibe et al. 2018).

Studies on childhood disability and families in Nigeria have identified financial burden as the most significant problem that impedes families in coping with the disabilities of their children (Ajuwon 2012; Ajuwon and Brown 2011). This makes many of such children to be deployed for alms-

begging (Etieyibo and Omiegebe 2016), while some of them are entirely abandoned by their families (Delaunay 2011). Aside from financial burden, authors have identified religion and culture as factors that make families with disabled children to experience distress in the process of providing care (Benyah 2017). This is especially reported in the case of children born with albinism, who are perceived to be abnormal, a curse, and evil by adherents of some traditional religions in the continent (Braathen and Ingstad 2006; Reimer-Kirkham et al. 2019).

Benyah (2017) reported that religious beliefs and cultural values contribute to the plights of albinos in Ghana. He posited that Africa as an enchanted space, where the worldview, beliefs and practices of people are largely influenced by their religious beliefs and convictions, it will be very difficult for families to deal with the stigmatization, discrimination and myths surrounding albinism and their subsequent nuances against PWA rights. In one of the sets of explanations of albinism that are linked to traditional animism in Nigeria, disabilities are said to be connected to punishments for bad deeds, or results of witchcraft (Ajuwon 2012). Therefore, families with members with albinism, who are adherents of such religion, may be influenced into regarding children with albinism as being born as a manifestation of their wrongdoings (Adedeji 2018).

### The Present Study

This study explores childhood experiences of PWA, in order to examine incidences of CWA's exposure to family-based discrimination and targeted violence due to their disability and social perceptions of albinos. Based on the postulation of the theory of 'othering,' it is imperative to examine the manner of interactions CWA have with other family members who are non-albinos. Meanwhile, there are avalanche of studies on families of children with disability that have largely excluded the peculiarities of children with albinism as a form of disability. This study is geared towards addressing the gap in literature on albinism, disability and family violence that are yet to significantly focus on the childhood experiences of PWA in their family environment.

### Method

#### Research Design

This research was set to deploy qualitative techniques, basically, due to the unexplored nature of the topic, and its identification as an emotive and complex issue. The study was aimed to capture breadth of experience and viewpoints of PWA in reliving their childhood experiences and viewpoints rather than commonality and dominant discourses.

Meanwhile, due to the sensitivity in discussing family-based violence, safety was considered important to this study, hence, group-setting for the research was not considered appropriate. There were sufficient structures in the interviews to address the research question, while flexibility was allowed in order for the thought processes of the participants to be pursued.

### Ethical Considerations

The study was conducted according to the guidelines of the Faculty of Social Sciences Research Ethics Committee, Olabisi Onabanjo University, which include voluntary participation, safeguards against participants' identity disclosure, respect for participants, confidentiality and anonymity. As a result, only the author knew those that took part in the interviews and all data were held securely according to the guidelines of the Ethics Committee. The participants were well briefed about the purpose of the study and their voluntary participation was sought at least two days before they were engaged in the interviews. Although, the study set out to examine the childhood experiences of PWA, children were exempted from the study for ethical reasons, considering the nature of the topic – which seeks information on family-based violence. All names used in the paper are pseudonyms selected by the participants themselves.

### Procedure

People living with albinism were interviewed about their family-based childhood experience, precisely concerning their treatment by other family members (parents, guardians, siblings, uncles, aunts, and other blood relatives) in relation to their albino condition. This research was approached with an interest in the nature of discriminatory attitudes, prejudice and violence exhibited by family members towards CWA as influenced by the social perceptions and attitudes against albinism. Also included is the perceived influence of religious inclinations towards the treatment of CWA by family members. We listened not only to how participants expressed their childhood experiences, but also for how they formulated these scripts as a way of discerning their growing-up years and their impressions about their treatments by other family members.

The study did not make use of any natural group, charity or organization in directly recruiting participants; so, in order to optimize diversity a varied approach was taken over a four-month period. In using this approach, invitation to participate in the study was posted on different websites and social media (in order to elicit nationwide participation), while posters were placed in community venues within Lagos metropolis (out of convenience), and advertisements were made on local radio. The help of social workers, religious and worship centers, and educators were also sought for the recruitment of participants through individual outreach to PWA with whom they related.

The call invited PWA that are 16 years and above to participate in interviews about their childhood experiences. In order to safeguard prospective participants, advertisements on radio, website and social media were not detailed about the aim of the study to elicit information on family violence. However, prospective participants were well briefed about the aim and purpose of the study after they made contacts with the interviewers.

The interviewers went to community venues, schools, restaurants and other public places to meet with prospective participants. The interviewers' team consisted of two males (including the author) and two females. The author made use of the services of three research assistants who were former students of the author, and were observing their mandatory one-year National Youth Service Corps program at the time of the data collection. Participants were given the choice to select the preferred gender (if they so wish) of their interviewer. Thirteen participants (11 women and 2 men) opted to make use of this offer. While the 11 women elected to be interviewed by female interviewers, the two men also preferred to be interviewed by female interviewers. However, we did not identify differential response patterns based on the gender match between interviewers and participants. Although, the study was a qualitative one, a socio-demographic questionnaire was completed by participants to inform the analysis, especially as regards family variables, and contextualize the narratives. Based on the assurance of confidentiality given to the participants, each interview was categorised and analysed with a nickname. The timing for the interviews ranged from 40 min to one hour 30 min. Eighteen participants received between N2,000 (approximately \$5) and N5,000 (approximately \$14) for their time and transport fare, while others declined the offer. Interviews were audio recorded and transcribed verbatim by the author, with the anonymized transcript imported into NVivo 12.

### Participants

The community of interest for this study were PWA who experienced their childhood in a family setting, either with their immediate family (parents and siblings) or with extended family (blood relatives, including families-in-laws, and step-family members). Therefore, the PWA who were raised in orphanages or similar institutions were excluded from the study. Due to the limited studies on the topic area, it was considered imperative to not only capture the information-rich cases, but to also attempt recruiting participants who might have a range of different experiences, beliefs and attitudes. Therefore, the maximum variation sampling was adopted. Maximum variation sampling is an approach that turns the problem of heterogeneity between individual cases in small samples from ostensible weakness to strength (Creswell 2013).

Although the information sought from the participants was centered on their childhood experiences, the eligibility for the participants was premised on attaining the age of 16 years because of the ethical constraints of engaging underage in a discussion on family based maltreatment. In addition, adult participation was considered more appropriate, since they would be able to share the full accounts of their childhood experiences, as against the underage that would still be in their childhood. Therefore, participants were tasked to recall their childhood and express their experience. Communication

during the interview was in British English, Pidgin English, Yoruba, Igbo and Hausa languages depending on the choice of the participants. The help of translators was obtained for three interviews conducted in Igbo and Hausa languages, as none of the interviewers could speak both languages fluently. Based on the importance of first-hand experience to this study, third party accounts were considered inappropriate (Table 1).

Sixty-two people with albinism, living in towns and rural areas across Nigeria, and between the ages of 18 and 61 ( $M = 25.62$ ;  $SD = 1.79$ ), were interviewed (38 women and 24 men),

**Table 1** Participants' sociodemographic characteristics

Variables	Total N=62	Percentage (%)
Age (years)		
18–24	23	37.1
25–31	14	22.6
32–38	11	17.7
39–45	4	6.5
46–52	6	9.7
53–59	2	3.2
>60	2	3.2
Gender		
Male	24	38.7
Female	38	61.3
Highest level of education		
None	9	14.5
Non-formal/Religious/literacy class/adult education	6	9.7
Primary school	5	8.1
Secondary/Technical/Teacher's College	32	51.6
Post-secondary	10	16.1
Ethnic Affiliation		
Yoruba	27	43.6
Igbo	11	17.7
Ijaw	8	12.9
Hausa	7	11.3
Others	9	14.5
Marital Status		
Single Never-Married	33	53.2
Married	12	19.3
Divorced/Separated	13	21.0
Widowed	4	6.5
Occupation		
Student (secondary and post-secondary)	6	9.7
Unemployed	29	46.8
Farming, petty trading, self-employed or artisan	13	21.0
Driver, motor park assistants, drivers' union officials, etc.	3	4.8
Teacher (primary and secondary schools)	2	3.2
Staff of government agencies and companies	5	8.1
Businessmen and self-employed professionals	4	6.5

Source: Field survey 2020

over a period of four months (December 2019 and March 2020). Twenty-seven interviews were conducted face-to-face, 18 over the phone, 11 using the WhatsApp video facility, and six using Skype (more electronic means of interviews were adopted for the month of March due to the spread of COVID-19 in Nigeria). The participants formed an ethnically diverse group, with slightly more than one-third (27) identifying as Yoruba, 11 identified as Igbo, 7 as Hausa, and 8 as Ijaw. The remaining nine participants identified with other six minority ethnic groups. In respect of their marital status, the majority of them were never-married single (33/62), while most of those that were married had fellow albino as spouse (9/12). The highest frequency of the participants were unemployed (29/62), despite being eligible to work, as only (6/62) were still in school as at the time of data collection.

### Interview Protocol

The interviews followed a semi-structured protocol designed to explore the family-based violence experienced by PWA in their childhood, based on prejudice over the state of their albinism. Interviewers asked the participants to recall and describe their perceived discriminatory treatments and unwarranted violence meted out to them, which they considered were prejudiced and based on underlining anger and resentment of their albino condition. Examples of these exploratory questions included: ‘What do you think an ideal early life experience of an individual would look like?’; ‘How will you describe the word ‘violence’?’; ‘In your growing up years, as a child, how would you describe your relationship with your family members – father, mother, siblings, other blood relatives that you lived with?’; and, ‘Do you in any way feel you were treated differently during your childhood – either positively or negatively?’

### Analysis Strategy

In the current study, emphases were laid on finding family-based violent treatments targeted at and meted out to children with albinism, as a result of the albino condition, and based on their difference from other family members. The research adopted inductive thematic analysis approach (Braun and Clarke 2006). The analyses started with the author reading through 15 transcripts, selected at random, and coded line-by-line using NVivo 12. The author then noted apparently common and contrasting thematic elements among the samples, and drafted a preliminary coding scheme. This initial codebook tracked the description of the participants of the word ‘violence,’ their choice of normalizing and/or problematizing themes in these accounts, and the information they shared about family maltreatment perceived by them.

In order to enhance the validity and reliability of the data and results, independent coding was done by two

academic staff (in the fields of psychology and sociology) that had earlier helped with the construct validity check for the research instrument. They examined the same 15 transcripts using the codebook. Thereafter, the author discussed the discrepancies with the independent coders in the conceptualizations, and the amendments of the coding scheme were done accordingly. The author and independent coders then separately coded all remaining transcripts. The Krippendorff’s Alpha coefficient was .918 for the agreement of the three coders. After the conclusion of the coding, the author met with the independent coders to resolve any discrepancies, so that there was mutual agreement on all applied codes.

## Results

### Characteristics of Participants’ Childhood Family Setting

Information about family variables were obtained from the participants in order to examine if these variables could have significant impact on the way the participants were treated within their family settings. The characteristics of the family as supplied by the study participants present diversity for the structure, size and birth order

As presented in Table 2.0, the majority of the participants (33.8%) spent their childhood within nuclear family setting where both parents lived together. However, a good number of them (16) spent their childhood with only one of their parents (single-parent). This category included seven participants that lost one of their parents through death (3), separation (3) and divorce (1), while nine were offspring of never-married mothers (7) and fathers (2). Eleven of them indicated they grew up in polygynous families where they lived with step-mothers and step-siblings. Out of these 11 participants, three of them stated that their mother was not present in the family (two absent due to divorce/separated and one due to death). Five participants spent most of their childhood with blood relatives from their mother’s (4) and father’s sides (1), while the remaining three participants lived with their maternal grandparents.

In respect of the number of siblings they had, the majority had between four to six siblings followed by those that had one to three, while six of them were the ‘only-child.’ A significant number of them (14) had at least 7 siblings. Meanwhile, as regards their position among their siblings, those that were older, together with the ‘only child’ group were slightly more (51.6%) than those that were younger among their siblings, together with middle-placed children (48.3%).

**Table 2** Characteristics of participants' family setting during childhood

Variables	Total N=62	Percentage (%)
Family type/structure		
Nuclear	21	33.9
Single-parent	16	25.8
Polygynous (with mother present)	8	12.9
Polygynous (without mother present)	3	4.9
Step family	6	9.7
Extended	5	8.1
Grandparent family	3	4.8
Number of siblings		
Only child	6	9.7
1–3	17	27.4
4–6	25	40.3
7–9	8	12.9
>10	6	9.7
Position among siblings		
Only child	6	9.7
Oldest brother of brothers	4	6.5
Youngest brother of brothers	9	14.5
Oldest brother of sisters	4	6.5
Youngest brother of sisters	3	4.8
Oldest sister of sisters	11	17.7
Youngest sister of sisters	8	12.9
Oldest sister of brothers	7	11.2
Youngest sister of brothers	5	8.1
The middle child	5	8.1

Source: Field survey 2020

## Findings

In an attempt to give context to the themes discussed in this section, it was considered necessary for the readers to understand the behaviors that perpetrators of family violence had exhibited against CWA within the context of their disability and negative social perception. When questions bordering around *violence*, *violent treatment* and *prejudice* were posed to the participants, they, themselves, recognized that they only knew a fraction of what constitute the concepts. While physical violence was widely acknowledged, the majority of the participants did not recognize verbal, emotional, economic (through deprivation of resources), spiritual, and social abuses as prejudicial. Therefore, interviewers enlightened them about the forms of abuse and prejudicial treatments within the scope of this study in order to elicit responses on related experiences from the participants. The participants were comfortable describing family-based experiences that they considered undesirable in their childhood and from a thematic analysis of the narratives, and the ways in which family members had behaved violently and prejudicially towards them were apparent.

Family members often employed tactics directly when prejudicing and behaving violently towards CWA, and these took a number of forms. The themes discussed below are: Perceived prejudice, disability-specific physical violence (actual and threatened), physical and psychological severity of violence and impact on family relationship, and coping strategies.

### Perceived Prejudice

All participants reported being at the receiving end of prejudice in their childhood from virtually all the family members they spent their growing up years with and on several occasions. They reported the prejudice to be a factor of their perceived and real disabilities, their different body features and distinction of their color from that of other family members. In respect of the perceived disabilities, participants reported that family members often regard them as unable to perform functions that involve minor physical strengths, the use of intellectual ability, and inability to eat spicy or salty foods. Azubuike, a male participant who grew up in a polygynous family with 14 members explained, as follows:

...sometimes when adults within the family needed help and called out for whomever that was around to come to their aid, If I should respond to such call, they would either laugh at me scornfully or tell me in clear terms that I did not belong to the category of people that can render any form of help to anybody. They never believed I had any form of physical strength to perform any duty. Even when I did things to prove them wrong, they would still hold on to their belief...

(Azubuike/middle child-9 siblings/polygynous family)

Meanwhile, as regards their real disabilities, like inability to see clearly under the sun or distant objects, involuntary back-and-forth movements of the eyes, inability to focus both eyes on a single object or point, sensitivity to light, or photophobia, the participants expressed that these disabilities were often exaggerated by family members when taunting them or calling them names such as 'low current,' 'monkey child,' 'spirit being,' and 'oosha-god.' Susan described her experience:

I was often made to feel like a non-human. Both my parents and brothers were always eager to talk about my disabilities. Sometimes they laughed about it, sometimes they didn't; but most times they exaggerate about it to ridicule me and keep me quiet. The funny thing is that they did not only say these things when they were angry with me alone. They even joked about it to make themselves and everyone laugh, except me.

(Susan/oldest child-3 siblings/nuclear family)

Other participants reported how prejudicial treatments led to their denial of continuous education or preferred vocation. Twenty-eight participants stated how their education was stopped by their parents at secondary and post-secondary levels due to their albinism. Nwakaego stated that she was the most brilliant among her siblings, but in her fourth year in secondary school, when she was asked to drop out from school for her three younger sisters and an older brother to continue their own education. She said her parents never told her it was because of her albino status but their words and body languages often implied that was the reason. Akintola stated: ‘my father had doubts that I will be employed because of my condition even if I had all the qualifications.’ Tina and three others reported that they were denied approval and/or resources to train or start their chosen vocation with statements like ‘you cannot be a caterer, who will buy food from an albino,’ ‘I don’t think people will want an albino to make their hair for them,’ ‘you don’t have the strength to be an auto mechanic, don’t deceive yourself,’ ‘*iru e ni won so ni?* – is it your kinds that are perceived to fit in?’

Aside from the real and perceived disabilities, participants reported that their parents and siblings expressed prejudice against them concerning the social perception of albinism and albinos. Thirty-two participants stated that they were stopped ‘many times’ from attending social gathering or outings that their siblings and other family members attended. Elias, an only male child with three sisters, reported how he was stopped from coming out to the living room of his house in order to attend a wedding program of his elder sister. Elias was denied access to the ceremony because his parents were apprehensive that if the family of the groom got to know that they (Elias’s family) had an albino child, ‘they may choose not to go ahead with the wedding, as they may fear my sister could also produce an albino for their son (the groom).’

On the issue of family’s perception of their social acceptance for marriage, Atinuke remarked:

My father used to say that while he will collect bride price from grooms that want to marry any of my sisters, in my own case, he will have to pay whichever man that is willing to marry me.

(Atinuke/ Second child-4 siblings/nuclear family)

Twelve participants out of those brought up by single parents (5), step families (3), extended families (2) and grandparents (2) indicated that their birth as albinos influenced the type of families they grew up in. These participants stated they were rejected by either their fathers (10) or both parents (2) at birth. Two of the five participants that were raised by single-parents stated that their birth (as albino) aborted the marriage plans between their mothers and fathers, while the remaining three stated that their already married parents separated (2) or divorced (1) on the account that their mother had them as

albino. Meanwhile, the majority of those who lived with both parents reported ‘frequent’ and ‘very frequent’ instances of arguments and quarrels between their mothers and fathers, with their albino status as subject of the quarrels. They mentioned hearing statements and remarks like ‘I don’t know where you brought him from,’ ‘we never had albinos in my lineage,’ ‘only God knows what you did to bring an albino home,’ and ‘you gave me three and a half children.’

### Disability-Specific Physical Violence (Actual and Threatened)

Participants largely reported different forms of violence, and of varied severity, meted out to them as children, mainly as a form of expressing ‘irritation,’ ‘disgust,’ ‘frustration,’ and ‘disapproval.’ All the participants stated that incidences of threatened violence were too many to recount, but they stated that physical violence specially visited on them based on resentment for their albino status are more memorable. The contexts of the violence in their childhood were premised on family maltreatment, superstitious beliefs, spiritually-induced beating based on the conception that they possessed evil spirit and must be delivered, and general irritation conceived by family members. Observable patterns from the responses of the participants are that those that were only children, and males of older ranks among their siblings reported less physical violence (within their disability context) from siblings as against females that were of older ranks with male younger siblings and middle or last born. Also, those that were brought up in polygynous families reported higher frequency of violence from both parents and siblings than others.

Omololu stated that he conceived the maltreatment he got from his parents and older siblings to be as a result of his albino status because most times when he was being beaten, ‘they make constant reference to my status as albino and their resentment for me because of my albinism.’ Chinedu explained that as a child, ‘blood relatives became easily irritated with my presence and often reacted by hitting me or throwing things at me just to ward me off.’ Hakeem, who was raised by his maternal relatives, stated that his aunt was fond of beating him with objects such as cane, sticks and belts, ‘largely because, as she often said, she was too irritated by me to touch or beat me with her bare hands.’ Aisha, who was also raised by her blood relatives, stated that her aunt often made reference to her being rejected by her father and abandoned by her mother because of her albinism.

Participants that had male older siblings reported more violent treatments from their siblings than those that had female older siblings. However, significant numbers of female participants who had male younger siblings reported being at the receiving end of physical violence from their younger brothers. Atinuke, who is a second child with three male younger siblings volunteered:



...my treatment from my younger brothers is as a result of the disrespect and disregard that are shown towards me by my parents. Meanwhile, since my brothers are physically stronger, they disrespect me and when I try to reprimand them, they resort to violence since I am considered weak by all. Meanwhile, rather than reprimand them, my parents will be abusing me for being too weak to even control my brothers.

(Atinuke/ Second child-4 siblings/nuclear family)

Participants also reported being subjected to spiritually-induced physical violence based on attempts to ‘deliver them from evil spirits that possessed them.’ These forms of violence which were visited on them mostly in Churches and other spiritual homes included being beaten with palm fronds, sticks, woods, iron rod, and other materials. Shalewa and two other participants reported that parts of their bodies like fingers, toes and palms were burnt with fire and their hairs shaved in a bid to stop their parents from further bringing forth albino children. Ndani narrated how he was made to sleep outside in the open for days in order to release the evil spirits he *possessed* ‘to the outer space.’

### Physical and Psychological Severity of Violence and Impact on Family Relationship

Participants were requested to volunteer information on the severity of the violence and prejudicial treatments they experienced, as well as the impact that such experiences had on their relationship with family members. Fifty-three of the participants selected ‘severe’ and ‘very severe’ and then provided details on the severity of the physical violence and prejudice they experienced based on their albino condition.

Based on the details provided by the participants, physical violence was considered ‘severe’ and ‘very severe’ if scars were left on their body from the maltreatment, and if they were hospitalized as a result of injuries or sickness that followed. On the other hand, prejudice from the family is considered ‘severe’ and ‘very severe’ if they suffered emotional breakdown for a lengthy period, if they were denied educational or vocational opportunities, if their self-esteem and confidence was affected, and if it was responsible for pushing them downward on the socioeconomic ladder. The majority of the participants stated that prejudice had more negative and long-lasting effect on them than the physical violence they suffered in their childhood. As Elias put it, ‘it left scars that never healed.’

Sixteen participants showed interviewers scars at different parts of their bodies to drive home their points on the severity of their childhood violent victimization, while eight participants claimed they had scars in parts of their bodies that cannot be revealed to the interviewers. Shalewa showed scars of her burnt fingers and toes suffered from the deliverance exercise that they went through.

I was in pains for weeks. My skin was badly damaged and I kept bleeding until I was eventually taken to the hospital against the instruction of the spiritualist. The spiritualist gave my parents instruction that I should be left to bleed, as that would break the bond I supposedly had with the unclean spirits. But after I passed out, I was rushed to the hospital.

(Shalewa/ First child-3 siblings/nuclear family)

Shalewa who was eight years old at the time of the incident was asked if her violent childhood experiences had any bearing with her current relationship with family members. She said, ‘well I have since forgiven them but I cannot simply forget.’ Fatai, one of an albino twin in a family with 8 children, narrated that he suffered more physical violence from his parents than his twin brother (who was also an albino), because he was more vocal in protesting against maltreatment and prejudice they were made to experience.

...my dad would lock me inside a room and beat me up till I became very weak. Since I was considered stubborn and rude, the entire family believed I possessed more evil spirit than that of my twin brother. My mother once said that I must have been the one that placed the curse of albinism on my twin brother inside her womb. My parents often rued the misfortune of having two albinos as twins and when I was being beaten, it was as if they were trying to get rid of me to reduce the albinos they had to deal with to just one.

(Fatai/ Twin Second-born-7 siblings/nuclear family)

Ife, who was one of those that indicated that their violent experience was ‘not too severe,’ stated that she was slapped many times because ‘I was always up to some form of mischief, and you know when you are being troubled by an albino, it looks like the spirits are after you (she laughed), so I understand being reprimanded.’ Similar to Ife’s response, eleven of those that selected ‘not too severe’ expressed the occasional violence they were subjected to by their parents, siblings and blood relatives. However, their choice of ‘not too severe’ was hinged on their sense of guilt and consideration that they deserved the punishment, or because they had forgiven the family members and decided to forget the incidents.

However, based on the impact of violence and prejudice experienced in their childhood on current family relationship, the majority of participants indicated that they were able to forgive and forget the physical violence than the emotional abuse that the prejudice against them caused. Nwakaego, whose secondary education was truncated, stated that she still held grudges against her parents for stopping her education in spite of her potentials and desire to further her education, just because ‘they feel as an albino, I stand no chance of returning investments on education.’ Although, Nwakaego eventually

completed her education, 21 participants stated they could not complete their education and held their parents responsible for it. Elias, who was denied access to his sister's wedding because the family did not want the groom's family to know they have an albino child, narrated how he refused to attend his father's burial six years later even though family members urged him to, 'if I wasn't good enough to appear for a wedding, then I would rather not attend the burial.'

Fifty-six participants stated that they still nursed some form of animosity against family members for the physical violence and prejudice they experienced in their childhood, even though the majority claimed they had forgiven them. In clarification, Atinuke stated, 'I forgave them but I still vent my anger whenever they feel they have any entitlement from me, I quickly remind them how they treated me...just to put them in their rightful place' Participants reported that they suffered more harm when prejudiced by family members than from neighbors or community members. Some of them expressed the difficulties they had been experiencing in forgiving and erasing the thoughts of the childhood experiences from their memory. Participants indicated they still had emotional/psychological problems like paranoia, anger, guilt, depression, feelings of powerlessness, withdrawal, low self-esteem, and worthlessness, as a result of their childhood experiences.

### Coping Strategies

In relating their childhood coping strategies against the prejudicial treatments and incidences of violence they had suffered, participants volunteered various ways which included 'spiritual consolation,' 'talking to the mirror' 'taking to drugs' 'confiding in friends,' 'simply accepting my faith,' 'the grace of God' 'laughing it out with them,' 'withdrawal from others,' and 'avoidance.' The majority of the participants indicated they learnt to avoid suffering physical violence and prejudice from their parents, siblings and other family members by keeping to themselves, avoiding to make contribution to family discussion and having minimal contacts with family members. Fifty-one out of the 57 that particularly adopted this strategy stated that it worked for them and kept them 'out of trouble.' The other six complained that it made them feel lonely and deprived them of benefits they would have enjoyed.

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

laughter and the one to vent their frustration on when they were not happy...

(Chinelo/ Last born-17 siblings/polygynous family)

Another strategy that 37 participants attested to its effectiveness was making friends with someone to share their emotion with. For 11 of them, as children, they created images on the mirrors or walls or had objects/items like teddy bears, pillows, chairs or imaginary images that they divulged their feelings to as *friends* after they had been victimized. Omolola, who reported prejudice and violence from her parents and siblings, explained that she had a permanent image of a girl she drew on her wall and named the image *ikejimi* (which in Yoruba language means *my second*). She reported she was born twins but her twin sister died before she attained two years of age. So she drew an image on the wall that represented her twin sister and reported to the image anytime she suffered any form of violence, abuse or prejudicial treatments. Fatai reported that he often took solace in discussing with his twin brother who also got treated badly and is an albino.

Seventeen participants indicated that they took to alcohol and drugs early in life, between age 8 and 14 as a result of the prejudicial treatment, emotional and physical violence and neglect they suffered. Japheth (36 years old), who reported he started drinking alcohol and smoking cigarette from 11 years, explained that he was able to make friends that shared his problem with him and proved valuable to him from drinking bars.

...they listened to me, they shared my pain and encouraged me to be full of hope for what the future will bring. It was strange to me that people who drink heavily as such could offer such advice of hope. But I always longed to hang around them and up till now we still relate well though we don't see physically that often...  
(Japheth/ Last born-17 siblings/polygynous family)

Fourteen participants developed the habit of taking sleeping drugs and other beverages that could induce sleep. Meanwhile, 18 participants took to non-harmful practices to cope with their emotional and physical pains such as chewing gums, drawing, reading books, praying, physical exercises, knitting and playing games. The participants spoke about how they developed these habits as an escape from the loneliness, maltreatment and prejudicial treatments they experienced in their childhood. Although, the majority stated that the coping techniques adopted by them worked, however, they indicated that they still felt lonely, unwanted, rejected, low self-worth and other emotional trauma that impacted on their personality, and even as adults.

## Discussion

This study aimed to document the childhood experiences of PWAs within their family setting in relation to prejudicial treatments and violence they underwent because of their albinism condition. Prior to the present study, community-based social discrimination, prejudice and violence meted out to PWAs had been the focus of most African studies on albinism (Benyah 2017; Cruz-Inigo et al. 2011; Reimer-Kirkham et al. 2019). However, these studies fail to pay adequate attention to the unique experiences of children. From the findings of this study, CWA are subjected to prejudice and violence within their families that are unique and equally deserving of research and intervention attention just as community-based victimization.

Parental acceptance of children born with albinism was found to be inadequate. Participants expressed that they were either rejected at birth by one or both of their parents, or made to suffer treatments exhibiting disapproval of their birth at home with their parents and siblings. Berk (2003) affirmed that self-esteem in children is built by warm, positive parenting, which makes them feel accepted as competent and worthwhile individuals. Meanwhile, in an earlier study where parental acceptance of CWA was found to be high, Kromberg et al. (1987) reported that the process of acceptance of children with oculocutaneous albinism by parents, especially the mothers, occurs slowly. The finding of this study on parental acceptance of CWA aligns with that of Machipisa (2002) who reported that the birth of a child born with albinism often caused conflicts in families, and sometimes led the fathers to reject the child or abandon their families.

In particular, prejudicial treatments were found among family members against CWA within the context of their real and perceived disabilities. These prejudices result in denials of educational opportunities, vocational training of their choosing, family relationship, social interactions especially with other children, and appearances in public gatherings. Unlike previous studies that reported community-based discrimination and violence as a major factor that impedes the education of PWA (Etieyibo and Omiegbe 2016; Franklin et al. 2018), results from this study suggest that family prejudice is a strong contributory factor. Parents were found to decline the continuous sponsoring of education to CWA based on the premise that they stand little chance of gaining employment after graduation. This notion further confirms the influence of society beliefs and attitudes towards albinism on parenting of CWA.

The study also found that the prejudices of family members against CWA are influenced by religious inclination and perceptions of albinism. Similar studies had reported the strength of religion as a factor determining the social perception of albino within African communities (Benyah 2017; Braathen and Ingstad 2006; Taylor et al. 2019). Participants attributed their perception as *evil* and *unfortunate* by family members to

social and religious beliefs about albinism within the society. This also influenced parental decisions on education, vocation and allowing CWA to participate in social activities and make public appearances.

In addition to the reported community-based violence that PWA are exposed to (Cruz-Inigo et al. 2011; Human Rights Watch 2019), the study found CWA to also be vulnerable to targeted physical violence within their family setting based on resentments extended to them as a result of their albinism condition. Family members, especially parents, were also found to facilitate physical violence visited on CWA in religious houses based on the beliefs that albinism is related to spiritual impurity and, therefore, CWA need to be delivered through violent means.

The study found *othering* in the family to impact strongly on the relationship that siblings and other members have with CWA, and this manifests in the prejudice and targeted violence against them. Studies have affirmed that people without albinism in sub-Saharan Africa engage in the ‘othering’ of PWA, perceiving them as *outsiders* within the black African communities (Braathen and Ingstad 2006; Cruz-Inigo et al. 2011; Reimer-Kirkham et al. 2019). Based on the result of this study, alienation and distancing of CWA by other family members aligns with the postulation of the theory and explains the basis for prejudice and targeted violence against CWA. This treatment was found to impact on their identity and self-esteem as a member of their family.

In the present study, participants reported emotional/psychological problems like paranoia, anger, shame, guilt, depression, feelings of powerlessness, withdrawal, low self-esteem, and low self-worth consequent on their childhood experiences of family-based violence and prejudicial treatments. This is consistent with the findings of some previous studies that experiences of discrimination, prejudice and violence by CWA may expose them to emotional and developmental problems. (Cruz-Inigo et al. 2011; Reimer-Kirkham et al. 2019). Participants identified the prejudice that negatively impacts on their life chances as generating more enduring negative feelings in their minds towards their family members than physical violence. This caused enduring strained relationship between them and their siblings and other family members.

Coping strategies contribute to reducing the level of victimization and alleviating the consequences of the abuse experience (Huang et al. 2008; Thoits 1995). Rutter (2000) suggested that a flexible and rich repertoire of strategies facilitates coping with different life challenges and complex traumatic situations. However, in this study, the coping strategies of CWA in navigating adverse family-based conditions as a result of their albinism condition were found to be diverse and emotion-oriented. Although, avoidance and emotion-oriented coping

strategies are seen as useful strategies for coping with physical abuse and experiencing or witnessing family violence (Sesar et al. 2010), they are considered ineffective and maladaptive coping strategies in the long term (Huang et al. 2008). In aligning with this position, study participants were found to still nurse enduring ill-feelings towards their family members based on their prejudicial childhood experiences.

### Policy, Practice and Research Implications

The findings of this study highlight the need for a review of measures designed to address the spate of discrimination, prejudice and violence encountered by people living with albinism within the Nigerian society to incorporate family-based interventions. In these interventions, family members (siblings, parents, blood relatives and significant others) should be oriented on the scientific cause of albinism and the need to empathize with children born with albinism and provide adequate care for them. In addition, screening for family violence against children with disability, and specifically, albinism should be incorporated into the primary duties of relevant agencies. Religious bodies should also be particularly engaged into programs enlightening the public on albinism and they should be advised to include positive treatments of children with disability into their religious tenets. Religious and social organizations should be saddled with the responsibilities of disabusing the minds of societal members as regards the evil ascriptions being attached to albinism in Nigeria.

At the community health level, education about how to care for CWA should not only be given to parents who had already given birth to albino children, such enlightenment should also be provided to all pregnant women at the ante-natal level in preparing their minds. Acceptance of CWA goes beyond absorbing them into the family but also eliminating any form of discrimination, inequality and prejudice against them, especially in their childhood, in order to enhance their self-esteem. There is a need for the government and other stakeholders to realize that prejudice and violence suffered by CWA at the family level has the tendency of leading to more enduring psychological disturbances than such treatments experienced at community level.

The government policy on albinism geared towards providing learning aids to CWA in schools should also extend its services to cover those who are withdrawn from school due to prejudice or parental financial incapability. The welfare of CWA designed and organized by government and other stakeholders should be attended to not just at the community level but also at the family level. Children with albinism that are abused within the family should also be guided to be able to report to appropriate

authorities and provided with counseling that will assist them in developing positively. Future research need to triangulate perspectives of parents, extended family members, and religious leaders with that of people living with albinism so that abusive family relationship experienced by CWA can be considered from multiple viewpoints. This will help broaden our understanding around perceptions of albinism, abuse and interventions.

### Study Limitations

One of the limitations of this research is that the sample lacked breadth for certain sociodemographic characteristics, ethnicity and socioeconomic classes in particular. Effort to examine the social class dimension of family violence and prejudice against CWA was not particularly successful. In addition, the opinion of CWA could not be included in the study, and adults who constituted the population of the study might have limited memory of their childhood or in forgiving the past, they might not volunteer all information concerning their experience. However, the key strength of this study is the novelty of the perspective because it accesses the experiences of PWA about their childhood, therefore bringing into light family-based experiences of children born with albinism that had been given limited attention.

### Conclusion

There is severe lack of rigorous empirical research into understanding the lives of CWA, especially from their perspectives and within their family setting. Their voice concerning the prejudicial treatments they were exposed to at the family level, the denial they experienced based on their social-relational disability, and what might better support, empower and protect CWA from family based victimizations have not been given much attention. The limited available evidence on living with albinism has mainly focused on their adulthood. This research has captured rich descriptions of the childhood experiences of PWA within their families, based on their interactions with parents, siblings, and extended family members. Findings have indicated that CWA are exposed to severe prejudice and violence from family members premised on their perceived disability, and that perpetrators use a variety of abusive tactics towards these people. An exploration of the knowledge on CWA within an integrated disability and family system lens will help to identify and frame the barriers encountered by this group and suggest possible ways to overcoming them. In addition, recognizing the predicaments of CWA will enable interventionists on discriminatory practices against this category of people to

better equip them in order to ensure that their safety, coping, self-esteem, and wellbeing are not compromised.

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