

Social discrimination against people with albinism

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Abstract

People with albinism have faced different forms of discrimination due to their genetic condition called oculocutaneous albinism. Oculocutaneous albinism, also known as OCA, is a genetic condition that results in people with low skin pigmentation and melanin levels in their hair, skin, and eyes to varying degrees. People who are afflicted with OCA have a high percentage of visual impairment and life-threatening sensitivity to the sun. Affected individuals also face negative outcomes of social, cultural, and economic prejudice because of the lack of color that their skin provides. People with albinism are shunned by the rest of their community and are at a high risk of being killed because of their unique physical features. The most common location where people with albinism are discriminated against is in Africa. In this exploratory study, research was conducted by interviewing four people with albinism to get an understanding of the social discrimination they faced. In these in-depth interviews, the focus was on the social aspect of their past and present lives and how they go about addressing any positive and/or negative outcomes they face in society because of their genetic condition. In addition, undergraduate students were surveyed from different fields of study to get an understanding of how much knowledge students have about albinism and its social aspects. Some of the majors surveyed include: biology, sociology, psychology, and liberal studies. The survey consisted of nine questions that were either multiple choice or true or false. The results of this research show that the people with albinism that were interviewed for this research have faced social discrimination within the societies they live in. The people that were interviewed were also from different locations in the country. The goal of the study is to bring awareness to the social struggles that people with albinism face in their everyday lives.

Keywords: Albinism, discrimination, blindness

Introduction

People with albinism (PWA) have faced different forms of discrimination due to their genetic condition called oculocutaneous albinism. Oculocutaneous albinism, also known as OCA, is a genetic condition that results in people with low skin pigmentation and melanin levels in their hair, skin, and eyes to varying degrees. People who are afflicted with OCA have a high percentage of visual impairment and life-threatening sensitivity to the sun. Affected individuals also face negative outcomes of social, cultural, and economic prejudice because of the lack of color that their skin provides. People with albinism are shunned away by the rest of their community and are at a high risk of being killed because of their unique physical features. The most common location where people with albinism are discriminated against is in Africa. In this exploratory study, research was conducted by interviewing four people with albinism to get an understanding of the social discrimination they faced. In these in-depth interviews, the focus was on the social aspect of their past and present lives and how they go about addressing any positive and/or negative outcomes they face in

society because of their genetic condition. In addition, undergraduate students from different fields of study were surveyed to get an understanding of how much knowledge students have about albinism and its social aspects. Some of the majors surveyed include: biology, sociology, psychology, and liberal studies. The survey consisted of nine questions that were either multiple choice or true or false. The results of this research show that the people with albinism that were interviewed for this research have faced social discrimination amongst the societies they live in. The people that were interviewed were also from different locations of the country. The goal of the study is to bring awareness to the social struggles that people with albinism face in their everyday lives.

Thesis

I am working on albinism to determine how they are socially discriminated against. In doing so, I hope to better understand the social, cultural norms, and expectations of people with albinism. I am going to go about it by interviewing people with albinism to discuss their personal situations. I expect my work will show

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that any type of prejudice or discrimination against people with albinism leads to the social, cultural, and political issues of affected individuals.

Literature review:

Myths/ Witch craft/ cultural beliefs

There are many common beliefs and myths that are associated to albinism in today's society. In an African society, when a baby with albinism is born, nurses are expected to talk to the mother of the baby with albinism to help ensure that the mother feels okay now that she has a baby with albinism. After labor, coming home to the husband and family is a difficult state of mind to be in. The majority of African American husbands of the baby with albinism usually blames the mother for cheating on him with another man, such as the tokolosh, or a malevolent spirit from Shona folklore which can be called upon to cause trouble for other people (Baker et al, 2010). In some cases, the husband will assume his wife has slept with a white man because of the pigmentation of the baby with albinism (Lund 2001). This results in the mother being in an abusive relationship, as well as dealing with the consequences that people believe it is her and her family's fault for having a baby with albinism (Lund, 2001). With these accusations, it is common for fathers to tell the mother to abandon, kill, or leave the baby to starve due to cultural beliefs and norms.

There are some myths such as, "people with albinism having magical superpowers, they can cure diseases like HIV, the devil stole the original child and replaced it with a person with albinism, and albinism is caused by a missing top layer of skin" (Cruz-Inigo et al, 2010). To add on, as tokolosh is indicated as an evil spirit, there are cultural beliefs that witchcraft is an essential way of killing PWA's to take their body parts in order to use for "magic" purposes, such as witchcraft potions (Brilliant, 2015). In other cases, there are marketers who sell albinism body parts that make charm bracelets because they are assumed to bring wealth and fortune to other individuals who have an albinism fetish or believe the myths (Burke et al, 2014). An incident that was reported on January 18th of 2015 stated that, "The body of Malita Makolija was found with head, arms and legs missing, buried near an anthill. She was 68 and had albinism" (Under the Same Sun, 2015).

Furthermore, the common myth in Africa is the fear of people with albinism being contagious. Families have kept their children away from children who have albinism because there is a fear that their child will become contagious and become a person with albinism as well. This proves a big problem knowing that people are believing in the myth that albinism is a sort of physical disability (Baker et al, 2010). The non-supportive societies and ideas in Africa believe that this

genetic disease can spread throughout Africa in no time because there is no treatment to prevent albinism from spreading (Baker et al, 2010). With that being said, those who are opposed to people with albinism consider that anything a person with albinism touches can be contaminated and poisoned, so it is important to keep away from them.

Another cultural myth is that people are spitting at those with albinism to help prevent any PWA being born within their families and to stay safe from the albinism community. The people that are most likely to spit at people with albinism are pregnant women, to ensure that her offspring will not come out as a PWA (Baker et al, 2010). With many common myths, PWA's are left to be isolated and turned away from their communities due to superstitions, cultural beliefs, and witchcraft.

Children

People with albinism face a challenging life; however, children are faced with discrimination more than others. The struggle for children is the lack of education in schools. Teachers and staff tend to stay away from children who have albinism due to the myths that PWA's are contagious (Lund, 2005). This is an issue that children will grow up to have little to no potential when living in a community where there is no support from the members of that population. In some instances, some children affected with albinism are not allowed to attend school (Baker, 2010). Since the majority of children with albinism cannot attend school, parents leave their children at home where it is safe to keep them where they will not be discriminated against. According to Lund, students from South Africa who are educated, attend special schools in order to help with their visual impairments (Lund, 2001). These special schools are to enhance how to be responsible and learn how to deal with their low visual impairment disabilities. Students who attend these schools are still able to fall back on school work because they are facing challenges of their visual impairments as well as being bullied by others who do not have a similar skin color as they do. Children with albinism are forced to be alone and others are expected to stay away from them because students are scared that children with albinism can be contagious. The most common bullies are the teachers. Teachers assign children with albinism to sit in the back as far as possible. For example, a teacher who was pregnant and feared that her baby would come out as albinism, so she placed the albinism student in the back of the class for the rest of the year (Metcalf, 2003, 139). On the other hand, students who are in poverty, are not able to attend special schools because they are in poor living conditions and communities. Another incident that was reported was in Malawi. The incident report states that, "On January 5, 2015, Mina Jeffrey was kidnapped by

three men, in Machinga district, Saiti Village. One of the kidnappers was her uncle. The 11-year-old managed to escape the men and was found. As a consequence of the incident, eleven school children with albinism have dropped out of different schools in the area, due to fears for their safety” (Under the Same Sun, 2015). Children with albinism who leave school may not get the same education as children who do not have albinism. With not enough education, children with albinism have a less likely chance of getting the job or career they want, or to even understand the basic necessities that involve education in their everyday lives.

Medical issues

There are two Oculocutaneous albinism types that are known: tyrosinase-negative (OCA1) and tyrosinase-positive (OCA2). According to Brilliant who is a researcher at Marshfield Clinic Research Foundation, “OCA1 is caused by a reduction or complete lack of activity of the tyrosinase enzyme encoded by the TYR gene. OCA2 is caused by a reduction or complete lack of activity of the P protein-a chloride channel that helps regulate the pH of the melanosome organelle where tyrosinase is active” (Brilliant, 2015). Within the two types of OCA, OCA2 is seen the most in African societies (van der Westhuizen, 2015). That being said, albinism is a genetic condition that can affect any individual of a family within a race, ethnicity, or gender. It is common to have two normal pigmented carrier parents to have an albino baby (Lund, 2005). Even though both parents carry the gene and do not have albinism, there is a high chance of their offspring having albinism. According to a study in Africa by Lund, “...the 35 villages visited in this study, 26 (74.3%) had at least one person with albinism” (Lund, 2007). With the population increasing, people with albinism are becoming aware of other medical and healthcare issues.

Studies have shown that people with albinism are more likely to face skin cancer as their age range develops throughout the years (Kromberg, 1989). With skin cancer, there are also freckle lesions that appear much more throughout the years, which distinguish the difference between people with albinism and other African Americans. People with albinism cannot afford to purchase sunscreen to help prevent skin cancer (Brilliant, 2015). This means that there are poor communities who have a higher rate of those with albinism. In the albinism community, they have low socioeconomic statuses, resulting in not having a sufficient amount of sunscreen to cure the skin cancer they are developing over their age range. With skin cancer, people with albinism do not live more than 30 to 40 years of age, leaving the albinism communities to shrink year after year. Although albinism is not curable, it is ideal that sunscreen is used to help maintain the skin cancer of the individuals (Lund, 2005). In other

impoverished areas of Africa, sunscreen is not available for purchase, making it difficult for affected individuals without access to healthcare resources. Within the impoverished communities, they are suggested to stay indoors and keep away from sun light as much as possible. With the help of little to no sun light, it is easier to maintain their skin cancer free without the use of sunscreen and not having to worry about how they can afford any treatment.

Social discrimination

Within areas of Africa, albinism is a common cause of discrimination. People with albinism are not seen as similar as others. They are instead seen as ‘different’ than those who are a part of the African population. People with albinism are expected to exclude themselves from the educational system, employment opportunities, transportation systems, and housing conditions (Barker et al, 2010). Because PWA’s are seen as a disgrace, they have a lack of access to healthcare and are low as a socioeconomic status. As a person, affected individuals cannot express their personalities or share their common interests with others because they face to be discrimination anywhere they are seen in public. An example is an individual who faces discrimination stated that, “You can only imagine what happened when I looked at myself as I walked past shop windows, in the rear view mirror; when I looked down, even for a moment, and saw glimpses of white and it didn’t fit with who I was” (Blankenberg, 2000). Within African societies, it is incumbent upon people with albinism to face the consequences of a challenging life because they are considered to be ‘different’ than other members of society. With the difficulty of excluding themselves from anything in society, people with albinism are also faced with the fact that they cannot have the life experiences of feeling a bond or relationship with others among their non-supportive community. The main perpetrators who discriminate people with albinism are family members who are unwilling to share their food and clothes with the affected individuals. Some discriminated people with albinism deal with getting beat to death, spat at, mocked, avoided by peers, and called a harsh name (Cruz-Inigo et al, 2011).

In addition, people with albinism have difficulties getting jobs due to their physical appearance and because they lack the sufficient amount of education or work experience. Also, they have poor visual impairments, which presents them from getting an occupation. Being unemployed leads to not having income. That is one of the main reasons that people with albinism are left to be impoverished and with low socioeconomic statuses. Although, those who manage to succeed in life, end up becoming successful at the occupations they achieved to perform.

Human rights

Discrimination amongst people with albinism has been an emerging topic about human rights, particularly in Africa. While rights are not considered to be a part of the albinism communities due to the different pigmentation in their skin color, African communities have continued to harass and socially discriminate against people with albinism. According to Burke et al, people with albinism are limited to exercise their rights as a human being (Burke et al, 2014). Not expressing the freedom to their human rights limits the ability to enjoy their freedom of expression or speech. In the Constitution of Tanzania, the international conventions on human rights, institutions of Tanzania's Commission for Human Rights, and Good Governance states the purposes of human rights explanations and characteristics (Burke et al, 2014). Within these articles, there are violations for criminals who commit any discrimination against people with albinism. With the help of the government, people with albinism are believed to have equal human rights with others. There are also activists who protest to stop the violations of human rights amongst people with albinism. These activists and supportive members of the community believe that people with albinism are, "...humans who deserve the same rights as others" (Burke et al, 2014). The ability of living and being a human being is the meaning of having the connection and bond with their community in order to share the common interests and cultural beliefs together as a unified whole. With the help, of having a social relationship within the community, PWA's are able to practice the significance of human rights. Burke also mentions that the way people treat each other is in the determination of having rights and it is in the wrongdoing to kill a human being who has no reason to be killed (Burke et al, 2014). This means that there are crimes committed due to people killing people with albinism for their body parts and having a cultural belief that their bodies bring a sacred meaning into fortune and wealth. It is described as, "people with albinism are slaughtered like chickens at the whims of wealth-hungry individuals" (Burke et al, 2014). This is a concern to the PWA communities who believe that their right to be human is in a crisis because their value in life is not appreciated to the majority of the community they are living in. However, some communities still disapprove of having people with albinism to have any part of human right expressions. With the help of the government still in place and rising, there are still issues such as: not doing enough protesting, making any action moves, or supporting victims who do not have a voice. According to Burke, "Rights are 'legitimate claims' involving three intersecting dimensions: social, legal and personal" (Burke et al, 2014). The social aspect provides the meaning of unity as a culture of the same beliefs through

each and every person in the community. The legal rights are focused on the intentions of the international and national laws that human right practices are made without the violation to commit any crime against people with albinism. The personal aspect is the value that people with albinism are understanding the main concept of what human rights means to them and the ability of what they are knowledgeable about. The media being in place to bring up the topic of albinism helps encourage public awareness activities of human rights for people who believe in the 'common humanity' within the community (Burke et al, 2014). Public awareness will contribute to stopping the harmful and violent accusations against people with albinism and stop affecting those who are loved ones that have to deal with the social, cultural, and political discrimination.

Solutions

There are numerous awareness campaigns dedicated to reducing albinism discrimination. These campaigns are organized to assist people with albinism with proper medical care and available resources to treat skin cancer (Cruz-Inigo et al, 2011). There are organizations and agencies that help improve environments for PWA who are feeling discriminated against. For example, the Tanzania Albino Center is an organization to help develop the surroundings of children with albinism within their living conditions and school settings. Another organization by the name of the World Health Organization, helps improve the health issues that are occurring to people with albinism who are unable to afford any sunscreen or other health treatments, such as burning of the skin and vision impairment of the eyes.

Method

I will search online, publicly accessible social media communities, such as Reddit, to recruit participants. I will find three or more individuals who are affected with albinism and live within the country. Once I find three or more individuals, I will email them to ask if they are interested on volunteering for a research project in regards to albinism. If they are, I will send them an informed consent form to sign and return to me in order to start the interview process. I will interview them through Skype, phone call, or in person, depending on the interviewee's availability. The interview will be a semi-structured interview that uses a list of questions prepared for the interviewees. The questionnaire will consist of 18 questions in total. The amount of time should range from 30 minutes to an hour depending on how long their responses are. I will take notes of every question they answer. They are able to skip questions they do not want to answer. The questions will relate to the social aspect of having

albinism. I will also distribute roughly 30 survey questionnaires to students at CSU Stanislaus through the Honors Program and other campus settings. I will find at least two people per major department to get a widespread idea of who is knowledgeable about albinism and the social aspects that can lead to discrimination. After inviting students to participate, I will briefly explain the project, give them the informed consent forms, answer any question they may have, and give them a written copy of the survey to fill out after they have signed the consent form. After they are done with the survey, I will collect it from them. The survey will consist of nine simple questions in total. Some questions will be true or false, some will be yes or no answers, and some will have an explanatory section for students to speak their minds.

Conclusion and future research

With the present study I am conducting, I will have at least three interviews with people who have albinism willing to volunteer in the research to get their experiences out in public. I am also hoping that knowing this is a timely manner study, it will be possible to get all the data needed to support the topic of albinism with the literature review I am doing. My results will show that the people with albinism that I interviewed have faced social discrimination among their society. I also anticipate to bring awareness to the social struggles that people with albinism face in their everyday lives.

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