Albinism: Cultural and Ethnographic Perspectives in a Southern City

Tabitha C. Green
Georgia State University

Follow this and additional works at: https://scholarworks.gsu.edu/anthro_theses

Recommended Citation
Green, Tabitha C., "Albinism: Cultural and Ethnographic Perspectives in a Southern City." Thesis, Georgia State University, 2017.
doi: https://doi.org/10.57709/11193826

This Thesis is brought to you for free and open access by the Department of Anthropology at ScholarWorks @ Georgia State University. It has been accepted for inclusion in Anthropology Theses by an authorized administrator of ScholarWorks @ Georgia State University. For more information, please contact scholarworks@gsu.edu.
ALBINISM: CULTURAL AND ETHNOGRAPHIC PERSPECTICES IN A SOUTHERN CITY

by

TABITHA CORRIN GREEN

Under the Direction of Bethany Turner-Livermore, PhD

ABSTRACT

This research is focused on the lived experience of individuals with albinism, both OCA (oculocutaneous albinism) and OA (ocular albinism). The cultural aspects of albinism are what will be primarily looked at during this study, as it is what the majority of the interview questions will be focused on. Following this will be a review of literature that is based on albinism, historical components, and how albinism has progressed over time. The main objective of this research is to aid in the reduction of stigmatization that is associated with albinism, further educate those who are unaware of the cultural complexities of albinism, and lastly to give agency to individuals with albinism through open ended interviews to share their lived experiences.

INDEX WORDS: Albinism, Oculocutaneous Albinism, Ocular Albinism, Skin, Pigmentation, African American, Blackness
ALBINISM: CULTURAL AND ETHNOGRAPHIC PERSPECTICES IN A SOUTHERN CITY

by

TABITHA CORRIN GREEN

A Thesis Submitted in Partial Fulfillment of the Requirements for the Degree of
Masters of Arts
in the College of Arts and Sciences
Georgia State University
2017
ALBINISM: CULTURAL AND ETHNOGRAPHIC PERSPECTICES IN A SOUTHERN CITY

by

TABITHA CORRIN GREEN

Committee Chair: Bethany Turner-Livermore

Committee: Cassandra White
Nina G. Jablonski

Electronic Version Approved:

Office of Graduate Studies
College of Arts and Sciences
Georgia State University
December 2017
DEDICATION

I am so humbled to have reached this point in my academic career. I would like to dedicate this to my late grandfather, Daniel Song, who served as my father and supported me through my academic career. I would also like to dedicate this to my mother, Chung A Song who has supported my through all of my academic endeavors, no matter how big or small, she has been there with me. This is also dedicated to my dog, Koko Green. Through all of my long nights of studying and reading, she was there for evening walks, and to bounce ideas off of, and emotional support even though she was not able to give verbal responses or edit any of my work.
ACKNOWLEDGEMENTS

I would like to thank Dr. Bethany Turner-Livermore, Dr. Cassandra White, and Dr. Nina G. Jablonski. These three women are all pillars in their respective disciplines of anthropology and I am honored to have worked with them through for my thesis. I would also like to acknowledge the Anthropology Department at Georgia State University for giving me access to a wide array of knowledge that I would otherwise not have had access to. I will forever be grateful and will take all of the skills with me into my career.
# TABLE OF CONTENTS

ACKNOWLEDGEMENTS ........................................................................................................... V

LIST OF TABLES ....................................................................................................................... VIII

LIST OF FIGURES ..................................................................................................................... IX

LIST OF ABBREVIATIONS ........................................................................................................ X

1 INTRODUCTION ....................................................................................................................... 1

1.1 Albinism in the United States ......................................................................................... 1

1.2 Purpose and Overarching Objectives .............................................................................. 2

2 ALBINISM AND BLACK IDENTITY ....................................................................................... 4

2.1 The African American Community and Albinism ......................................................... 4

2.1.1 Social Media and Skin Conditions ............................................................................. 7

2.1.2 Blackness in the United States – What Does It Mean to be “Black”? ............. 17

2.2 “Too Black to be White, Too White to be Black” ...................................................... 18

3 BIOCULTURAL ASPECTS OF ALBINISM ........................................................................ 18

3.1 Clinical Aspects .............................................................................................................. 19

3.1.1 Value and Skin Tones ................................................................................................. 24

3.2 Albinism as a Public Health Issue (Issues Within the Health System) ...................... 26

3.2.1 The Body and How it is Viewed Within Different Health Systems ................. 27

4 METHODS ............................................................................................................................. 29

4.1 Research Questions ......................................................................................................... 33
4.1.1  In-Depth Interview Questions ................................................................. 33
4.1.2  Survey Questions .................................................................................... 34
4.2    Limitations ............................................................................................... 35
4.3    Significance .............................................................................................. 37
5      RESULTS .................................................................................................. 37
5.1    Interviews and Surveys Limitations ......................................................... 37
      5.1.1  Recruitment Methods Limitations ...................................................... 38
      5.1.2  Interview Results .............................................................................. 40
5.2    “Albinism is not a Disability; it is a Condition” ...................................... 45
5.3    Survey Results ........................................................................................ 46
6      DISCUSSION AND CONCLUSIONS ....................................................... 49
      6.1    Discussions ...................................................................................... 49
      6.2    Future Research ............................................................................... 51
REFERENCES .................................................................................................... 53
APPENDICES ..................................................................................................... 56
Appendix A: IRB ............................................................................................... 56
Appendix A.1: Informed Consent Form ............................................................ 56
Appendix A.2: Informed Consent - Survey ....................................................... 57
Appendix B – Informed Consent ..................................................................... 58
Appendix C – Survey ....................................................................................... 59
LIST OF TABLES

Table 1 Description of Oculocutaneous Albinism from NIH type 1-4........................................ 22

Table 2 Qualtrics Survey Results............................................................................................... 46
LIST OF FIGURES

Figure 1 Lil Yatchy’s Teenage Emotion Album Cover .......................................................... 7
Figure 2 Royal Romance MAC ......................................................................................... 9
Figure 3 Winnie Harlow (Chantelle Brown-Young) ............................................................ 9
Figure 4 Shaun Ross ......................................................................................................... 11
Figure 5 Lara and Mara Bawar ........................................................................................ 12
Figure 6 Michael Jackson and Skin Transitions ............................................................... 14
Figure 7 Ocular Albinism Iris .......................................................................................... 22
LIST OF ABBREVIATIONS

OCA – Oculocutaneous Albinism
OA – Ocular Albinism
NIH – National institutes of Health
UV – Ultraviolet
UVR – Ultraviolet radiation
INTRODUCTION

1.1 Albinism in the United States

Skin tone is much more complex than what is on the outside of the body. Skin tone can determine a lot within the United States. In the case of Albinism, it can determine what ethnic or social group and individual feels comfortable identifying with or even what group will accept the individual. Albinism is a condition that many individuals are unaware of as it is not necessarily common in certain areas of the United States. Albinism is a genetic condition and there are two forms, Oculocutaneous albinism (OCA) and Ocular albinism (OA). Albinism is a skin condition that affects the eyes, skin and hair. For those with this skin condition, health issues heavy exposure to sun can cause certain health risks such as sun burn and skin cancer. Apart from the physical risks that albinism can bring, many do not factor in how it affects the social life of an individual. Albinism has caused violence and led to hunting in countries where their body parts are believed to be good luck. In the United States, those with albinism have been ridiculed due to their skin tone which has led to unfair treatment in employment, issues with acceptance, and difficulty with self-identification. This may bring into question what counts as black identity as some say they have been told they are “too white to be black or too black to be white”, which is later stated in one of the interviews.

Although albinism can cause issues with acceptance, many have recently been accepted in different communities that were recently not. In the modeling community, individuals with skin conditions such as vitiligo and albinism are being introduced as it was not common for models with these skin conditions were not common to this industry. Models new to this industry are Winnie Harlow, Shaun Ross, and the Bawar twins. These models have all entered this
community and have been opening a new platform as they have shown that all skin tones should be accepted. With this being said, products are used to lighten skin tones as some individuals of darker skin tones are not pleased with their skin tone and believe that lighter skin tones are more appealing due to standards set by society. From an anthropological perspective, this study is significant as it looks at albinism is viewed within the black community. Identifying as Black or African American within the United States, there are aspects that being a minority that can become difficult for individuals due to their skin tone. Identifying as albino and African American within the U.S. however, can be considered a double minority which can cause issues both inside and outside of the African American community. The significance of this study is how individuals in the United States view skin tones pertaining to albinism in relation to how individuals navigate through society as they may face certain issues with identification and self-identification, acceptance, or even violence or trauma they may face.

1.2 Purpose and Overarching Objectives

This researched focused on the lived experiences of African Americans with albinism in the United States and with the ultimate goal to give agency to those with albinism. This research was based on ethnographic research paired with a literature review. From my research, many individuals have not been given an outlet to speak about their individual battles they have dealt with in from discrimination, visual impairment, bullying, et cetera. All of my participants are a part of the African American community, yet many have faced discrimination within the community and while majority of them may identify with the community, some lack trust with the community due to years of discrimination, lack of support, and issues with acceptance.
Through this study, I intend to contribute to the research of albinism by further educating those who may not know about albinism through reducing stigma, and breaking any social harm that may be within or between groups that may have been formed over the years. The key questions for this thesis are:

1. How do individuals with albinism varyingly self-identify?

   [Different kinds of manifestations, some people “pass” while others cannot or do not care to identify…changes over time in the US about how albinism is talked about, etc.]

2. Do individuals have support through their community and/or family, and what precautions are taken in terms of daily life, if any?

   [Eye issues include: reduced pigmentation of the epithelium cells, misroutining of the optic nerves at the chiasm, photophobia, and nystagmus…Skin issues include: skin cancers and sunburn…Social risks: stigma, marginalization, violence, being hunted for their body and limbs, executions, socially unaccepted by African American community, discrimination in the workplace]

The research involved interviews and a survey that were approved by the Institutional Review Board (IRB) through Georgia State University. Interviews were conducted over Skype videoconferencing software to create a more uniform study. Each interview lasted one to two hours long and was scripted to ensure each participant understood the study and no information misunderstood. Notes were taken during the interviews and later used grounded theory analysis to identify themes that emerged from data. Within the in-depth interviews, it was crucial to identify my part within the interview as I was an equal part of the interview process. As the researcher of this ethnography, it was important to identify my position in relation to those who I
was interviewing as I am not apart of the albino community. While I am part African American, I am not an individual that is living with albinism and it was important that I acknowledged this for myself and for those that I was interviewing. It was important for my participants to be aware that I was an individual in academia from the U.S. that was not a part of the albino community as I was not completely immersed in certain aspects that are associated with albinism. By doing this, I had to self-identify myself as a woman who is both African American and Korean descent as I was working with individuals who I was not necessarily able to completely identify with.

Within this thesis, I will go over black identity as my participants were all part of the African American community, and how those with albinism may identify, the biocultural aspects of albinism, and the methods that were used to conduct the research. The results from this research yielded both results from interviews and surveys as well as methodological limitations that were encountered during the interview and survey process. Following this is the discussion and future research that I believe could be done to further added to held contribute to the research of albinism.

\section{Albinism and Black Identity}

\subsection{The African American Community and Albinism}

In the African American community, I have witnessed and experienced a form of internal segregation that distinguishes those of lighter skin tones from those of darker skin tones. It has been noted that Blacks with lighter skin tones tend to be of higher status than those of darker skin tones (Keith, Harring 2010).
The African American community has derived a preference for light skin over time. “When social messages and elevated social status are associated with images of people with lighter skin (as in much advertising), the effects are swift and sure (Jablonski 2012: 158.) The African American community has a social hierarchy that is constructed and can create a status due to color, but is not yet understood as referenced by Uzogara and Lee. This began during slavery where “lighter-skinned slaves were usually mixed-raced and favored by White slave-owners” (Uzogara and Lee 2015: 2). Today, this mentality continues, but is used within the African American community. Many see those with lighter skin as favored by White Americans and even favored by those within the African American community. In the African American community, there has been a power structure created due to skin tones that ranges from darker to lighter. “For example, many African Americans once endorsed the idea that darker-skinned African Americans were inherently inferior to lighter-skinned African Americans (Gatewood, 1988; Okazawa-Rey, Robinson. & Ward, 1986) (Clark, Andersson, & Clark et al. 1999: 806). People who are of a lighter complexion are usually compared to those within the White community and statements such as “lighter skin people are prettier” have been used to describe individuals. This can be attributed to how “light skin and European features are the gold standard for beauty and desirability…” as stated by Harris (2008). The phrase “lighter skin is prettier” tends to be used more with women than with men, and is even used within families as we are a patriarchal society. There are three general terms that are used to describe those within the Black or African Community: light skin, medium, or dark skin. Terms that parallel with these are “red/red bone” (Gillmer 2010), “yellow/yellow bone”, and “black skin” and can be heard and seen more in media today. While these terms are not medical, they are used within the construct that was created within the African American community. Verbiage like this creates a form of
Colorism within the African American community and their skin. Colorism is the way in which individuals discriminate against others based on the means of skin color and nothing else.

“Colorism and traditional U.S. racism are inextricably intertwined, yet distinct. Racism involves discrimination against persons based on their racial identity…” (Harris 2008: 54). Colorism is a form of pure visual discrimination. Colorism in often linked to that of socioeconomic status as those who are lighter, or closer to White, may be seen as higher performers or higher performers in society while those who are of darker skin tones may be viewed as opposite, and this is not true. This is similar to that of caste systems seen in India. While they do not necessarily use skin tone to segregate their caste system, they base theirs upon types of labor ones family does. In relation to skin tone, the caste system as a group called the untouchables, which would be considered outcasts and those would be considered those who do not “fit in”. In the case of this research, those with albinism may fall in that spectrum as they have been pushed to the periphery from the Africa American community.

Within the African American community, there is deeply rooted, spoken and even unspoken, understanding in how those identify with skin tone and identify within self and others. This can begin either as a child and is taught from the family or is learned as adults as individuals begin to identify with different micro groups as adults. Those within the African American community take pride in their skin tone as individuals, and also form micro communities that are based upon specific skin tones, such a light skin, medium skin or dark skin groups. While these groups may not be groups that you find online, they exist within the African American community today and are strict. These communities are what also form specific Black identities and also further segregate other Black identities.
2.1.1 Social Media and Skin Conditions

In the media today, it is more common to see individuals with varying skin tones and conditions including different skin conditions/hyperpigmentation’s, such as albinism or vitiligo in the media, as shown in figure 1. Musician Lil Yachty recently included a young man who has albinism and a young woman who has vitiligo on his album cover for his latest release called Teenage Emotions. Vitiligo is not generally shown in pop culture which may be due to how vitiligo is perceived – as a disorder or even a disease. This musician is the first to expose individuals with different skin conditions, but specifically those with vitiligo. The lack of

Figure 1 Lil Yatchy’s Teenage Emotion Album Cover

In the media today, it is more common to see individuals with varying skin tones and conditions including different skin conditions/hyperpigmentation’s, such as albinism or vitiligo in the media, as shown in figure 1. Musician Lil Yachty recently included a young man who has albinism and a young woman who has vitiligo on his album cover for his latest release called Teenage Emotions. Vitiligo is not generally shown in pop culture which may be due to how vitiligo is perceived – as a disorder or even a disease. This musician is the first to expose individuals with different skin conditions, but specifically those with vitiligo. The lack of
acceptance in the African American community and others towards individuals with skin conditions that drift from the “visual norm” in terms of skin tone has been fairly high. For a well known musician such as Lil Yatchy to give exposure to those with vitiligo and albinism has shed light on individuals opens doors within pop culture and possibly other avenues. Pop culture reaches a variety of people and can allow people to contemplate on those who are all involved and become more accepting. During an interview he did in response to criticism for the album cover, Lil Yachty, the 21-year-old Atlanta musician, stated that:

“I wanted to have all aspects of teenage life...so I thought about all the things I saw in high school for the first time, that I had never experienced before” “I’ve never seen albino kids until high school, I’ve never seen emo kids until high school”.

While Lil Yachty brought exposure to individuals into the music industry, the beauty industry has expanded their definitions of beauty as well, but has struggled due to their “definitions” of what beauty is as it has been standardized over the years. In media, specifically in the beauty industry, issues have risen due to specific issues with women of color. Mac Cosmetics recently came under social backlash last year for a photo relating to an African American woman and one Mac’s lipsticks shades, in figure 2.
The photo included a woman wearing MAC’s “Royal Romance” lipstick for New York Fashion Week and there were racial slurs and hatefulness said towards the model due to her full lips and her darker skin pigmentation. The main issue that was stated was that people who were inside and outside of the makeup community did not believe that it did not show the “true” shade of “Royal Romance”. But why is it that the makeup community did not accept this woman for her features and not believe that this is how the shade should have been represented?

Figure 2 Royal Romance MAC

Figure 3 Winnie Harlow (Chantelle Brown-Young)
Winnie Harlow and Shaun Ross are two fashion models who are praised for their looks. When both of these models were introduced to the industry, commentators would constantly question their skin tones, but for models without albinism or vitiligo, their skin was never question. While obvious their skin differs, why would their skin need to be questioned when they are modeling clothing? It raises the question of why their skin is brought into question for “beauty.” Chantelle Brown-Young, professionally known as Winnie Harlow who is shown in figure 3, is a Jamaican-Canadian model with vitiligo and has both been praised and ridiculed by the African American community due to her skin condition. In an interview Harlow did, she recalled that she wanted to make new friends when she moved to a new school, but “kids called me a cow and mooed at me”, which made making new friends difficult. Vitiligo is a skin condition that is known to cause “irregular white spots or patches on the skin” (Roy 2017: 1). This can be seen as similar to albinism (in appearance, at least) as these patches lack are areas of depigmentation and can cover small areas of the body or be more widespread such as that of Winnie Harlow. Part of this is due to how her vitiligo has presented as symmetrical on her facial region and on parts of her arms. Harlow may not have albinism, but her skin condition makes her “different” as her skin does not necessarily conform to the rest of the African American community or Jamaican; therefore, she has been ridiculed. On the other side of this, due to her beauty, she has found praise through her career as her depigmentation has been found visually appealing to those of the media eye. I want to raise the question that is if her skin depigmentation that is considered appealing to those in the media, or is it that she is being fetishized for how her skin presents differently, yet still symmetrical. For Harlow, her acceptance was found through modeling, but this may only be specific to her as she is a model and those viewing her may find her skin depigmentation a visual fetish as it is the first time they have seen a model with this skin
condition. For those with vitiligo, the perception may vary. Vitiligo is not something that is invisible to the naked eye. For those with small patches of vitiligo and a lighter base skin tone, they may not be judged as harshly as those with a darker base skin tone. For those with lighter skin tones with vitiligo, it may appear that they are peeling from sun burn and others may not judge them as it is less noticeable. For those with darker base skin tones, vitiligo may appear as symptoms of a disorder or a disease due to the skin color contrast. For Winnie Harlow, this was the case as she was bullied. While she would still be considered Black or African American in the community, she may also be seen as an outcast due her her skin condition, unfortunately.

Similar to this is the American model Shaun Ross, seen in figure 4.

Figure 4 Shaun Ross
Ross is an African American model from the Bronx who has faced much stigmatization due to his skin tone but has also found a way to capitalize on it. During an interview Ross did with Elle, he shared that he was an outcast and the only “light-skinned” student in a high school class of 500+ students. While being bullied, he did not allow find this as something that he would use as
a “PR-friendly copout” (Hyman 2013). He states that while many people do anti-bullying campaigns, he thanks those who bullied his as it made him who he is today, and he even created a hashtag on social media for this (#inmyownskiniwin). He is best known for being the first male albino model and has been featured in GQ. While he may be African American, he has faced ostracism due to his skin tone as those within his community have not accepted him due to his skin tone. While Ross is fully albino, he is still African American but his lack of pigmentation has created a disconnect between him and the community. Luckily, Ross was able to turn his condition into something that benefited him and even opened doors for others with similar skin conditions such as the Bawar twins.

Figure 5 Lara and Mara Bawar
New to the face of modeling today is Lara and Mara Bawar. These two young women are twins that recently walked into the modeling scene with albinism. Similar to Shaun Ross, they both have albinism. While Ross and Harlow have faced different issues within the modeling industry, these two models have seen a different side to the industry as children. For children, no matter their age or ethnic background, growing up can be difficult. For children with albinism, growing up can be very difficult as other children tend to bully kids who are seen as different. Ross and Winnie have faced this even as adults. These twins stated in their interview that they believe that “albinism is pretty” and that they love their “hair, eye color and skin tone”. These two models have embraced albinism and will continue to show that no matter the skin tone, you should embrace your differences.
Figure 6 Michael Jackson and Skin Transitions

The last example of colorism that has been expressed in recent years has been that of the late Michael Jackson, in figure 6. Michael Jackson has been known throughout the music community as an African American male who was born with a medium skin tone similar to the rest of his siblings. Due to his battle with vitiligo spreading, many believed that he began the process of skin lightening or skin bleaching (James 2009). Skin bleaching with products such as Porcelana or other bleach cream products that are sold in health clinics and are easily accessible without a prescription is not uncommon, as many feel that lighter skin may be more attractive or acceptable within the African American community. While the theory of lightening the entire face or body stands true in some countries or for some individuals within the United States, skin lightening is not something that is necessarily done to
lighten the entire body. Today, there are products that are used for spot treatment such as face creams or washes that contain retinal which reduces dark spots on the skin. Products such as these do not aim to alter the skin tone drastically, or bleach. Most of these products do not need a prescription and can be found in skin care sections. For African Americans, the marketing for skin lightening products may be deceiving as they may use verbiage such as “lighten” or “brighten” and the products may only be found in an aisle of the store where other “ethnic” or skin products made for those of people of color may be sold. Jackson’s skin transition from his condition came as a surprise to the African American community and the misunderstanding of his skin condition leading many to not accept him in the community. This can be seen as a form of structural intraracial racism due to color. Social and community acceptance, or lack thereof, based on color is not solely a problem within the United States as it can be seen in other countries. While it can be seen in examples with Ms. Harlow, Mr. Ross, and the late Michael Jackson, these issues are world wide as it pushes people with albinism out of a community.

Similar issues can be seen around the world, thus creating a structural global issue. Baker et al. (2010) states that in much of Africa, those with albinism are excluded from more than just their community, rather they are excluded from getting an education, employment, transportation and healthcare. The question I raise is what causes this form of resentment towards those with albinism? Individuals that live in areas with populations of albino people may have misconceptions or fear of those with albinism or lack knowledge to understand what albinism is and is not. As a student in the southeastern United States, albinism was not taught about as a part of the curriculum. Historically, in countries such as South Africa, skin color has always created a divide between those of white complexions and what we consider black or darker skin complexions:
Racial (and colour) differentiation is best illustrated by referring to some of the repealed apartheid statutes that significantly affected the black community in South Africa, such as the Black Administration Act (our emphasis)... Elsewhere, Section 1(1) of the Population Registration Act defined a black person as ‘a person who is, or is generally accepted as, a member of any aboriginal race or tribe of Africa’ (Mswela 2013: 25-26).

In South Africa, people of darker or black skin are the majority (in terms of population) and those of white skin tones are the minority. Mswela (2013) describes how the community dictates who is and is not accepted into a community. Acceptance in this community is what can create a racial divide and people with albinism may not be accepted by those of the black community in this community based on skin tone. Acceptance was not always a matter of choice, but was dictated by law. Both the Black Administration Act and Population Registration Acts were active prior to the abolition of apartheid. While these acts are no longer in place today, their impact still reverberates through South Africa. While the lack of pigmentation can lead to a separation between a community, information on what albinism is from a biomedical perspective may help to break down myths and is important as it can help reduce stigmatization and marginalization. For many to understand albinism, there has to be a form of education that is shared. Marginalization has always been a problem with the albino community (Mucina 2015). For women who give birth to children who have albinism, there is blame placed on the mother of either infidelity or that the mother touched someone with albinism (Baker et al. 2010). For childbearing women and people in the community alike, being knowledgeable of albinism may help break down the stereotypes and myths that surround albinism.
2.1.2 Blackness in the United States – What Does It Mean to be “Black”?  

As a young mixed African American women living in the United States, the question “what does it mean to be black” is complex as there is no single definition to it – it is fluid, yet there are certain “criteria” or determinants of blackness within the United States. The question “are you black”? or “how black are you”? are questions that run a spectrum. Do these questions pose a true answer, and if so, are they questions that have a correct answer? For an individual who may answer yes, their answer may be derived from skin color, self-identification and awareness, how one was raised, and community acceptance. While an individual may be born into an African American family or even adopted by one, blackness is not something that an individual may or may not have. For an African American individual with albinism, this may become a more complicated issues as they may feel less inclined self-identify with the African American community and may possibly identify with another group. Sandra, who did not identify her age nor her occupation, stated how she felt about the self-identification:

“For me, I knew I was Black, but I hung out with all of the Latinos because they knew I was black, but they did not judge me by my skin tone like the other Black kids did. I didn’t speak Spanish, so they taught me and that’s how I identified myself. Today, my kids speak Spanish and I still self-identify as Hispanic.”

For any individual within the African American community, particularly with albinism, who is questioned about their blackness, it raises the issue of who is attempting to define their blackness and their blackness and why their blackness questioned. When an individual questions one blackness, they are then trying to define what blackness is, when blackness truly has no true
definition. Problematically, when an individual does this, they do not realize that they can place who they ask in a box by attempting to define their blackness, as every person who self identifies as “Black” does not have the same definition.

2.2 “Too Black to be White, Too White to be Black”

For any individual within the African American community, particularly with albinism, who is questioned about their blackness, it raises the issue of who is attempting to define their blackness and their blackness and why their blackness questioned. When an individual questions one’s blackness, they are then trying to define what blackness is, when blackness truly has no empirical definition. Problematically, when an individual does this, they do not realize that they can place who they ask in a box by attempting to define their blackness, as every person who self identifies as “Black” does not have the same definition.

3 BIOCULTURAL ASPECTS OF ALBINISM

Albinism is a skin condition but depending on what are of the world one is in, it has been classified as a condition, a disease, a disorder, or a disability. While it is understood as a skin condition in the medical community, different cultures have a different understanding on how albinism is inherited, what it means, how it is spread from one person to another, or how it can affect someone. In some African cultures, albinism has been surrounded by myths, some of which include that albinism is spread in the same manner as human immunodeficiency virus (HIV) infection and that albinism is caused by a missing top layer of skin (Cruz-Ingo 2011). Specific to Tanzania, a young woman named Grace who was interviewed stated that she was in constant fear during election time as she would be hunted for her body or body parts as myth says it would help people win the election (Oduah 2017). In These myths are culturally specific and are ways that different cultures understand albinism. Culturally, individuals with albinism
have been called racial slurs and terms. In Zimbabwe, they have been called “sope” which suggests that they are inhabited by evil spirits; in Tanzania they have been called “zeru”, which means ghost; “mzungu” white person; or “nguruwe” which means pig (Cruz-Ingo 2011: 81). These myths and terms amongst others are common misconceptions in which people may understand albinism or how people believe albinism affects those and individuals around them. More importantly, these terms are ways in which people classify those with albinism, which further segregates and marginalizes those with this condition. For an individual with albinism, in a country where those who deal with marginalization due to their skin tone, it can alter their acceptance and quality of life, specifically medically. In some countries, similar to the United States, most practitioners are trained to look for the source of the sickness, pain, or illness. As someone who deals with albinism, marginalization and ridicule can affect the levels of stress in daily life. Individuals with albinism lack pigmentation and while they may not necessarily be African or African American, those that I will focus on for this example will be. In the following section, I will focus on how different medical practitioners view the body and how it is perceived within different communities in relation to albinism.

3.1 Clinical Aspects

Skin, the largest organ of the body has three layers. The outermost layer is the epidermis which visually has hair, the layer beneath it is the dermis, and the innermost layer is subcutaneous layer. Together, these three layers work to protect the body. “It [skin] performs many vital functions, including protection against external physical, chemical, and biologic assailants, as well as prevention of excess water loss from the body and a role in thermoregulation” (Kolarsick, Kolarsick & Goodwin 2011: 203). As skin has this role to protect the body, pigmentation is what helps against UV radiation but can also create social and class
divide between people. For those with albinism, the skin is compromised as it lacks the pigmentation to ward off the harmful rays. Albinism is a clinical condition that affects the hair, skin, and eyes. Albinism comes in two forms, oculocutaneous albinism (OCA) and ocular albinism (OA). In laymen’s terms, albinism is a condition that takes away the skin color, hair color, and reduces the vision of an individual. This condition is non-discriminatory as it does not just affect those of African American descent. Respectively, OCA reduces pigmentation in the hair, eyes and skin and can leave the individual with visual impairment while OA causes visual impairments. These two forms affect the body differently; ocular albinism is mainly presented in the eyes while oculocutaneous can affect the eyes, hair, and skin. “In humans, at least four genes (TYR, OCA2, TYRP1, and MATP) are responsible for different types of the condition and can exert their effects at various points in the biochemical pathways that produce pigmentation, affecting the production of eumelanin and pheomelanin” (Jablonski 2012: 16).

Albinism is a significant public health issue as it decreases the body's defense to ultraviolet radiation which can result in ocular impairment and skin cancers. While there are many myths that surround this clinical condition about how albinism is given or spread, “albinism is an autosomal recessive condition meaning that 2 copies of an albinism gene - one inherited from each parent - must be present in order for someone to be born with albinism (Jablonski 2012: 16). Albinism, as the overarching term, is what is used to describe both oculocutaneous albinism (OCA) and ocular albinism (OA). Many common phenotypic characteristics that are associated with that of oculocutaneous albinism are an absence of melanin or very pale skin tone. For those with ocular albinism seen in figure 5, the common trait will be visual acuity or visual impairments that also reduces pigmentation of the iris (Gronskov, Ek, and
Brondum-Nielsen 2007). Oculocutaneous albinism, OCA, has four types which is described in table 1 with information from the National Institutes of Health (NIH).
Table 1 Description of Oculocutaneous Albinism from NIH type 1-4

<table>
<thead>
<tr>
<th>Type</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Type 1</td>
<td>White hair, pale skin, lightly colored irises</td>
</tr>
<tr>
<td>Type 2</td>
<td>Less “severe” than type 1, skin is considered creamy white. Hair: light yellow, blonde, light brown</td>
</tr>
<tr>
<td>Type 3</td>
<td>“Rufous” Oculocutaneous albinism. This form generally affects dark-skinned individuals. Individuals have reddish-brown skin tones, ginger or red hair, and hazel or brown irises. This form is often associated with milder vision abnormalities than other forms of OCA.</td>
</tr>
<tr>
<td>Type 4</td>
<td>Has signs and symptoms similar to type 2</td>
</tr>
</tbody>
</table>

The most common form of ocular albinism is known as Nettleship-Falls or type 1. This results from a mutation from the GPR143 gene which provides instructions for the making of a protein that helps creating a protein that produces pigmentation, as explained by NIH.

Figure 7 Ocular Albinism Iris
For individuals with oculocutaneous albinism (OCA), the loss of pigmentation can be a health issue as it leaves the skin exposed to the sun. This form of exposure not only leaves the skin at
risk for cancer, but also the eyes. The lack of pigmentation can cause issues with how an individual navigates socially as it can determine how or where one can work. For one with albinism, working outdoors or living in areas that lack shade would jeopardize their health as it would increase the risk factor of sunburn and possible skin cancers.

Albinism is a skin condition that may make someone more sensitive to sunlight. Melanin, which is produced by cells called melanocytes, is what provides skin pigment. When someone has albinism, their melanocytes produce little to no melanin, which leaves them with no protection against the sun and this can cause life long issues such as cancer. Yakubu and Mabogunje (1993) did a study of 773 Africans, 18 of which were albino. Their study focused on Africans in Nigeria that were considered normally pigmented and Africans that were albino and a link to cancer. Those that were normally pigmented did indeed have cancer but at an older age range. “Albino patients in the present study were much younger than normally pigmented skin cancer patients. This may be due to the underlying genetic abnormality. All the albinos had head and neck tumors and 2 patients also had trunk lesions” (Yakubu and Mabogunje 1993: 622).

Variables such as amounts of sun exposure, lifestyle, and where one lives in reference to the equator can affect the risk of cancer related issues. Alexander and Henschke (1981:1047) found “in a recent survey of nearly 1,000 patients with albinism [in Africa] that no albino over the age of 20 years was free of malignant or premalignant skin disease” (Alexander & Henschke 1981: 1047). Problematically, those who live in certain parts of Africa (and tropical areas in general) and are albino may fall victim to squamous cell carcinomas or possible basal cell carcinomas. Visual impairments for those with albinism include foveal hypoplasia, reduced pigmentation of epithelium cells, misrouting of the optic nerves at the chiasm, reduced pigmentation in the iris, photophobia, and nystagmus (Groskov et al., 2007; Martinez-Garcia and
Montoliu, 2013; Summers, 2009). For use of protection, people with oculocutaneous albinism can protect their skin and face by wearing sunblock, hats, and UV protection clothing. For individuals with ocular albinism protecting their eyes, wearing sunglasses that are big enough to protect the front and side of the eyes is ideal.

### 3.1.1 Value and Skin Tones

In our culture today, values are created to explain the worth of an object or labor and can also help give meaning to something. In the case of Graeber, the term “value” is ambiguous and can lead to complications in how the value of one object is understood. From one culture to another, the value of something can change, similar to currency. The flaw with the term “value” is that its concept is abstract, and there is no true and solid way to define value without creating a comparison between two objects, or in this case, two or more people. In terms of albinism, values may be placed upon someone to compare their skin and body in relation to an individual that is not living with albinism.

The conversation of an individual when it pertains to the skin has become problematized as it places a value on the skin tone. It is imperative to understand the value of any persons is not dependent or determined on the bases of skin color. Skin color has become a factor in many societies, especially in the United States that has altered ways in which people navigate through life and social class systems. Marx, referenced by Graeber, argues that “the value of commodities is derived from the human labor that went into producing them…” (Graeber 2010: 26), but this idea can be placed upon people. For people who are albino in Tanzania, there has been a market created that places an economic value on pieces of an individual. In 2007, witchdoctors made potions with the blood albinos, shoes from their skin, and other objects that would be intertwined with their hair (Bucaro 2010: 133). This turns individuals into marketable
entities, but not for their labor, rather the labor that is expected of what can be produced from their body. While those that are albino have portions of themselves sold on the black market, their value as a human being has diminished as they are not seen as people, but as those that can be hunted, and their value as an object to be sold has increased.

No individual should be considered less valuable as a person due to their skin tone. Those who are albino have value as a whole person, and due to their skin tone they are placed in a different position than others – an economic one. Once individuals with albinism are put into an economic position such as an amulet, a magic potion, or are hunted for their body parts the value is no longer about the person as an individual, but the value is placed on what the person’s parts are capable of. In the case of Tanzania, people with this condition lost a sense of their social value, as they were seen as omens of disaster, as mentioned by Bucaro. The idea that value can be ascribed by others and taken away simply from one's skin tone creates a power structure in which those who have albinism are going to be seen as a “negative value”. This also allows those who are not a part of the albino community to place themselves in a higher position - a hierarchy. The structure of how an albino individual can be placed below an individual show that the initial value that was placed on albino people is a cultural construct that diminishes the value of the person.

3.1.1.1 Stigma and Marginalization

For individuals who have albinism, the ongoing issue of skin tone and stigma is paired together. Within the context of albinism in African American community in the United States, my participants revealed that their stigmatization came in two forms. One from the fact that they
were African American and the other that they were albino. Being African American in the United States as stated by one of my participants, Meredith, is difficult as she believes there is a level of distrust. To be albino and African American in the United States creates was said to add more issues of distrust and even issues within the African American community as it created a form of internal segregation. While skin tone should not create stigmatization, marginalization, or one to be pushed to the periphery in any community, it does in many cases. In the United States, it does in the African American community and those with albinism may face this issue. For those with albinism, their condition has been surrounded by myths, a lack of understanding, and structures that allow those to be harmed for the “betterment” of others. All of these issues here and in other countries dictate the lived experience of one with albinism lives and socially navigates. With the information presented, it will provide a baseline understanding of how individuals with albinism that will be involved in my own study may or may not feel or have viewed their own albinism today.

3.2 Albinism as a Public Health Issue (Issues Within the Health System)

Albinism, while it is not a disability such as dyslexia or a ADHD, it is a condition that I will analyze as a public health issue. Albinism can create health issues that are not always recognized by employers or can even be taken advantage of in certain cases. For example, one of the questions I asked participants was:

Did your job or employer consider your condition a disability or treat you any differently from your counterparts?

Jon, a 64-year-old academic believe that he was treated differently and that he even lost his job due to albinism.
I didn’t consider it a disability, but it is a disabling condition. I believe I was fired from my job [principle] due to albinism, but I have no recorded proof of this. I was accused of accepting a hug from a subordinate which is considered sexual harassment as a principle, so I was fired. I was offered the position of curriculum specialist, but I did not want this as it was a step down.

3.2.1 The Body and How it is Viewed Within Different Health Systems

In each society, the role of a person can be seen as a single entity or as a body that aids in the structural integrity of the community. The body itself can be seen as a capsule that holds organs and belongs only to the individual, but here I will demonstrate ways in which the body may be more holistic, political, and social, rather than atomistic. Scheper-Hughes and Lock (1987) explain the “three bodies” (the individual body, the social body, and the body politic) to understand the lived experience of a person.

The individual body analysis is a way that many Western practitioners and clinicians understand a patient and their illness (Scheper-Hughes, Lock 1987: 8). For those with albinism, they experience forms of marginalization and stigmatization may cause stress or anxiety that they may want to speak to their doctor or general care practitioner about. A medical practitioner may not consider marginalization and as “relevant” information while diagnosing causes of stress, rather the practitioner may look for other variables such as work, family, or other environmental related issues.

In this analysis, much of the extraneous information that is given during a diagnosis by the patient may be disregarded. Many medical students or professionals may be less concerned with
information that does not concern functions of the body, and more concerned with what the
“real” cause of the illness is due to their training in Western medicine. While Western medicine
does help for many diseases such as cancer, if a patient believes that the cancer is caused by a
spell placed on them, voodoo, or through other means, this information may be found unrelated
to the diagnoses which can cause mistrust in the doctor or even lead to the patient to stop coming
as the patient may feel disregarded. The individual body analysis does not work for every culture
as it can undermine significant information that can lead to a correct diagnosis. In a culture that
does not practice Western medicine, this analysis of the body can place an ethnocentric view of
how the body should be diagnosed and even healed and does not allow for non-medical
perspectives.

The second, the **social body**, can be paralleled to that of an archaeological artifact such as
a projectile point. It is a symbol, but natural, and used to think of nature, culture, and society as
suggested by Mary Douglas. For example, in Mt. Kaata in Bolivia, the Qollahuayas see people
and the mountains as one: “Sickness is caused by disruptions between people and the
land…”(Schepet-Hughes, Lock 1987: 20). As a culture, they see that a disruption in their social
bodies are more important than the individual - they take a holistic approach to the body, the
land, and society. To treat an illness, the body of the individual and the mountain must be
restored to its healthy state. The analysis of the social body has a great benefit as it holds the
holistic approach to the community and places no one before another; this ensures that the
community will be looked after before the individual. The downside to this is that an individual
who is sick and disrupts the health of the community may not receive the care that is needed, as
the focus will be on the community. Similar to this approach is the body politic as it integrates
the community into some aspects of care.
The third, the **body politic** as stated by its name, refers to “the regulation, surveillance, and control of bodies (individual and collective) in reproduction and sexuality, in work and in leisure, in sickness and other forms of deviance and human differences (Schepers-Hughes, Lock 1987: 20). In many cases, people who cannot afford health care or do not have access can fall victim to being controlled, or their body being analyzed by the body politic. This leads them to regulation by society or the community. In certain cases, regulation can happen through an ethnocentric beliefs or attitudes that are affect others. The body politic can be seen in the albino community, but in a different light. A common popular belief about those with albinism is that parts of their body hold superpowers and can cure diseases for others in areas of sub-Saharan Africa, Tanzania, and East Africa as documented by Cruz-Ingo (2011). These misconceptions lead to those with albinism be targeted and for their body to be used for potions or amulets. Regulation of the body in this manner takes away the civil and natural rights of one with albinism and gives it to a collective to delegate what should be done with the body. Regardless of one having albinism, the individual should have a voice in what should be done with their body.

### 4 METHODS

In this chapter, address the data collection, the interview process, the survey collection process, data analysis, any ethical challenges that I may or may not have faced, and the significance of this research. Collection of data that informed this research was done through a literature review and through open-ended interviews. The interview process of this thesis was done in the summer of 2017 and the writing portion of this thesis began in August 2017 and its completion will be in December of 2017. There was a total of 4 participants in this study for the interviews, all of which participated within the surveys, and 1 new individual who participated within the survey.
While I did not intend to restrict my research strictly to Georgia, all of my participants were from the same geographical area. Participants for the study were all over the age of 18 and include both males and females.

To reach participants, multiple avenues were used. One approach that was used was word of mouth, rather through respondent driven sampling (Bernard 2011: 147-148). To maintain confidentiality of the other participant’s personal information, no information was shared with any third party persons. For this process, individuals who knew those with albinism were able to give my information to possible participants. I did not reach out to those that will be a possible participant through a third party as it was unethical.

For surveys, all participants were contacted initially via social media or through word of mouth. Through this, I was able to get into contact with 5 participants, 4 of which were participants for the interviews. When participants agreed upon interest, they provided their personal email address where a follow-up email was sent with the IRB form was sent with all of the information then the link to Qualtrics was sent which further explained what the survey entailed. The survey link had all information that was submitted to the IRB which explained the aspects of the study, any possible risks, what the survey entailed, and the amount of time allotted in for the survey. For the survey, each participant had an unlimited amount of time to complete the survey. The Survey began with a consent form prior to letting participants continuing into the questionnaire. This page had a consent button along with a button that allowed participants to opt out of the study placed at the bottom which allowed each participant read over all information and required
each participant click to continue. There was no interaction between the participants and myself after I sent the Qualtrics link to the participants.

This study did not limit the location in which the participant lived as the goal was not to isolate participants with albinism to one location. After trying to find participants, both in and out of state, I was only able to locate participants within state. Email contact was initiated with a self introduction and a recruitment script. The recruitment script allowed participants to read over what they were going to be a part of and a basic overview of what the study entailed. Paired with this was informed consent form where participants were able to sign.

For in-depth interviews, when agreed upon to be a part of the study, a Skype call or phone call if necessary through a secure line was made to obtain verbal consent to ensure that the individual wants to participate in the study. As verbal consent was given, an informed consent form was emailed to the participants’ private email for the participant to sign and send back as it will be necessary prior to beginning the study. This form clearly spelled out procedures that took place during the study, any risks that were involved, benefits, compensation, voluntary participation and withdrawal, how the participant were kept confidential, and who to contact if there are any questions, comments or concerns at any stage of the study. At that stage, participants signed the informed consent form. The email was sent back to a firewall safe computer and saved to a file with a specific code assigned to each participant. All information was saved onto an external hard drive to ensure that information was not lost in the case of computer failure.
For privacy of both the participant and the nature of the study, face to face interviews would have been in an agreed upon space and an audio recording would have been taken. Due to how my participants requested their interviews, there were no face to face interviews. For Skype interviews, it was asked that both the interviewer (myself) and the interviewee was in quiet room that is private from others so that all information was kept private. All interview participants were given a pseudonym to protect their identity as this study asked questions that pertained to health related and personal histories. For all interviews, field notes were taken as a log to aid in coding similarities and differences between each person’s life experiences. Participants had the option to choose not to be recorded and we notified at the beginning of the interview that they would be recorded and had the option not to be. Notes during the interview included information on the how the interview was taken, the length of the interview, and answers that were given during the interview were later used in writing this research. During this process, a photo was asked to be given as a part of the interview process and the participant was able to deny providing a photo. As part of the IRB, the participant was asked to sign to consent for their photo to be used as a part of the research/study.

Data was collected through interviews and later analyzed. During interviews, there were audio recordings, if allowed by the participant, and field notes taken during each interview. Each set of field notes include the date of the interview and body language and tone that was used during the interview. As described by Erving Goffman (1956), the performance given by the individual is crucial and can even be determined by the social setting that one is on or the individuals that one is around. How one presents themselves during the interview is important to how their
information is conveyed. Field notes were reviewed and sorted by the age and region of the interviewee as well. From my review of the notes, all of my participants were from Atlanta, Georgia and were in the same age range. This helped to create a system to organize the interviews and better understand results as a group and help located the types of experiences individuals have regionally as well as if there are any generational differences in the experiences had as well as any themes. I used field notes and interviews for data analysis.

4.1 Research Questions

My research questions were geared to gain a general understanding of how each participant has lived with albinism, if they have been discriminated against, how they view albinism, and to give each one a voice. I believe that each participant should have a safe space to be allowed to speak about their condition without being judged, nor stigmatized due to their skin condition. I also believe that each of my questions for individuals to explore how they view themselves and well as how they believe how they are viewed within their community. Each research question in section 4.1.1. was asked in a way that would allow the participants to give more life-based answers in conversation, while the questions in section 4.1.2 gave limitation in how they were answered.

4.1.1 In-Depth Interview Questions

Question 1: How do you self-identify? Do you define yourself as an individual with albinism, or an individual as a part of an ethnic group with a different skin tone?

Question 2: What gender do you self-identify with?

Question 3: Which form of albinism you have?
Question 4: At what age were you taught about your albinism? Were you taught about its genetic differences and how it may affect you? Do you see yourself as different from others? Can you talk about that more?

Question 5: Have you experienced any special or different treatment as an individual with albinism? Have you ever been discriminated against as an individual with albinism? If so, can you please share an experience.

Question 6: Are there other individuals within your family that have albinism? If so, who, and how have their experiences affected you?

Question 7: Do you consider albinism a form of disability? If so, why? Has it hindered you from accomplishing any tasks?

Question 8: Who were those that have supported you/helped you the most? Do you find that you needed any support?

Question 9: What are the positive outcomes of having albinism/being an albino individual?

Question 10: In contrast, what are any negatives that you have experienced with having albinism if any?

Question 11: Are there any experiences where you had to explain albinism to an individual?

Question 12: Would you feel comfortable with submitting a photograph of yourself? This can be one of you in everyday life (such as a selfie, out to dinner, out and about, etc.)

4.1.2 Survey Questions

Question 1: How old are you? (Numerical)

Question 2: What is your gender?

Question 3: Do you have children?

Question 4: Do you work outdoors (not within an office space)?
**Question 5**: Do you self-identify as Albino?

**Question 6**: What form of Albinism do you have? OCA or OA?

**Question 7**: What is your racial/ethnic identity?

**Question 8**: Do you consider albinism a form of disability? If so, why?

**Question 9**: Has albinism hindered you from accomplishing any tasks?

**Question 10**: Does having albinism affect how others perceive you in terms of race or ethnicity? Does this affect your self-perception?

**Question 11**: Do you have to take special precautions in daily life because of albinism? If so, what are they?

**Question 12**: Have you ever been discriminated against as an individual with albinism? If so, can you please share an experience.

**Question 13**: Does anyone in your family have albinism?

**Question 14**: If you needed support, do you have support a support system (i.e. friends, family, mentors)?

### 4.2 Limitations

Due to the nature of this study, ethical issues were a concern as as individuals may have been sensitive to the questions as it may have triggered emotions, memories, or feeling(s) of stigmatization or racial profiling. Certain questions such as if albinism is considered a disability or if has hindered any daily life tasks may cause emotional distress or may have caused the participant to become anxious, upset, or defensive. During a few interviews, participants had to clarify the question(s) to ensure that they were not being pinpointed for their genetic condition. I had to reassure them that it was solely for research purposes and that I was not prying nor trying
to raise any previous or hidden trauma that may have occurred in their past. These questions were not meant to create or cause any emotional harm to the participant, rather it is to help each participant think about albinism in a different light while giving an ethnographic perspective of the condition without compromising any of the information due to emotional distress.

One of my goals during the data collection process was to ensure that each participant felt comfortable with every question that was addressed. For any discomfort that any participant may have felt during the duration of the study, the participant was allowed to speak to me at any time. I accommodated them in any way possible that does not jeopardize the integrity of the study.

This study may have been limited in the amount of information that was gathered as participants had the option to not answer questions due to discomfort. Other limitations may have been due to communication or to schedule conflict. While this study was aimed to gather the lived experience of at least 10 participants, gathering 10 participants was difficult as participants many may not have wanted to self-report themselves as albino or have been identified by other they knew by their stories. Another possible issue was that during this study, each participant may find that they no longer want their information published after their interview was completed and want to retract all of their data gathered. This both limits the amount of participants involved within the study and ethnographic data. The goal of this thesis is to help break any stigma that has been associated with albinism and any interviews that are done are significant as it helps further give a voice for this community.
4.3 Significance

The significance of this study lies in the ethnographic accounts of different participants with albinism and how they have grown into their personhood compared to the review of literature and historical context of albinism. This study is crucial because there are individuals with albinism in the United States that struggle with coping mechanisms and finding ways to express their condition, self-identification, and finding ways of support. Part and parcel of this, there are individuals in other countries that may face exile or ridicule due to their appearance. With this study, my intention is to identify both challenges that people with albinism face and coping mechanisms and support systems that allow some people with this condition to better navigate their daily lives. This could have implications for parents of children with albinism and for future public health interventions in the U.S. and elsewhere. Along with this, there is a significance in learning if participants have had a chance to have an open dialogue about their condition. This study is for meant for academic purposes, but I intend for this study to be mutualistic as it can help those within the study as it can give them agency to share their story.

5 RESULTS

5.1 Interviews and Surveys Limitations

While gathering qualitative and quantitative data from my research, I encountered some difficulties as I did not gather data from as many people as expected which I believe may have left room for misinterpretation. I was only able to conduct four in-depth Skype interviews and five surveys while the maximum number for interviews I wanted to conduct was 10 and for surveys was 50. I was not able to speak with or survey as many people as I would have liked, but through the interactions that I did have, I was still able to gather valuable information.
5.1.1 Recruitment Methods Limitations

During my interview process, my initial sample size goal was 10 or more, as stated in chapter 4. While recruiting, finding my initial participants was not difficult as they knew each other via a support group that I reached out to. Each participant that I interviewed was easy to contact and were eager to help with my research. One recruitment error that was unexpected was that the level of stigma that surrounds albinism may have prevented individuals from wanting to either be interviewed or participant in a survey. The stigma that surrounds albinism is not to be taken lightly as it has reverberated through many communities and the interactions between individuals could cause more damage than good. “The consequences of a presentation that is perforce made to the public at large may be small in particular contacts, but in every contact there will be some consequences, which, taken together, can be immense” (Goffman 1963: 48). Here, Goffman shows how each interaction, or in my case, the reading of the research may be small in the grand scheme of things, but the exposure of each individuals’ story can be immense as their story is personal, their particular condition has already been stigmatized, and the aftermath can be immense. What I also did not take into account was that I am an Asian African American woman. While I did not go into my research with this as a factor, I believe that this may have played into part of the research. During one of my interviews, one participants asked me my ethnic background, and informed me that I would not understand the struggles that African Americans go through as I have the privilege of being mixed which led me to believe that either my appearance or ethnic background may alter the amount of participants I was able to have or the information I was able to gather.

For the surveys, I had no interaction with individuals who would potentially take them. While the surveys were anonymous, the albino community in Georgia is not that big and some
participants may have felt that they were being stigmatized and even placed into a medical study by being interviewed in any capacity by someone who does not have albinism. This feeling of being “medicalized” can stem from how the skin condition has been heavily researched mainly by doctors, but not a lot by social scientists. Dreger (2000) explains how those within the medical community may not notice, but those involved in medical treatments such as those of altering their sexual organs, are viewed as “medical exhibitions” and may even feel as though they are solely being viewed for their body, and nothing more. “Although it was certainly not the medical professionals’ intentions, these “exhibitions” had left the subjects feeling freakish and violated- “like insects tacked to a board for study” (Dreger 2000: 162). Another issue with being interviewed within the albino community is that individuals may felt that they would have been easily identified though their stories. For most individuals with albinism, their stories are very specific, and identification through specific phrases or mentioning of life history could cause identification and that feeling of having their personal stories turned into an “exhibit” for research is the main thing I did not want to do as it would shatter the rapport between myself and participants.

To begin recruiting, I reached out to individuals within the group, as I believed they would have felt comfortable with speaking to someone who had rapport with anyone within the group. My assumptions led me to a few dead ends. For my anonymous surveys, I distributed a link via social media site, as stated through IRB. I believe that those who read the survey consent form may have felt either offended or felt that they were being pinpointed for a survey that did not include others that did not have albinism. While the IRB was completely professional in how it informed participants in what they would be involved in, I believe the way the information that was included in the IRB turned some people away and that was an error on my part. I believe
having an informational video or audio clip would have made this process more personalized for individuals, as they would have felt less “studied” or stigmatized/studied. To reduce this feeling of being stigmatized, I believe I could have expanded my research to all African Americans and gathered their insight on those with albinism and created a cross-cultural comparison. With this, I believe that individuals may have felt less stigmatized as they would have felt more included in a bigger population.

Another issue during the interview process was the communication prior and during the interview. With one of my participants, my interview was split in half due to interruption during the interview, but was later continued and finished. While scheduling the interviews, most of my participants had scheduling errors which led to 2 of my possible participants to drop out of being interviewed. The scheduling issues were due to work or personal conflict, which was respected as I was on their time, but still needed to have results in following a strict timeline. While scheduling my interviews, we would set a date and time and the call would be placed then and recorded. The main issue I ran into with scheduling was participants would forget our scheduled time and would want to push the interview to a later time, which would create a schedule conflict. When setting up the interview, I would send an email with the day and time or set the time up over the phone. This was an error on my part, as I believe setting up a time and date on a Google calendar and sending it to each participant and sending it to them as a reminder could have alleviated any timing issues that the participant and I had.

5.1.2 Interview Results

My first in-depth interview was with Meredith. Meredith is a 41-year-old woman from Atlanta, Georgia who is a business entrepreneur who has OCA1B. When asked about how she self-identifies, Meredith did not identify as a woman with albinism, but she identifies with her
name and ethnic background. “I’m an African American woman first, and everything else is secondary”. This was a common answer throughout all of the interviews, as all of the interviewees do not believe that their albinism should be the way that they identify themselves, rather they identify with their ethnicity or race. Meredith and I talked for roughly two hours about how her childhood shaped her adult life and how it taught her that she could not allow others and their commentary to define how she sees herself. As a child, she was not necessarily taught about her albinism, but later in life around 25, she began to do her own research about albinism as she wanted to gain a better understanding about her skin condition, what precautions she would possibly need to take, and what this would mean for her life and lifestyle. With albinism, while there are specialists such as dermatologists and general practitioners, who can teach you how to prevent sunburn, but “there is not a doctor or profession that can teach you how albinism will affect you”, as she stated. Due to her albinism, she has a visual impairment that requires reasonable accommodations. Currently, she works at a local clothing store part-time where she has faced some discrimination where other individuals were asked to do tasks because individuals there believe that all albino individuals are blind. At this point, she knew that there were not many positives not negatives that came from albinism, but she did learn that you cannot let this condition control your life, which I did perceive as a positive.

Jon, an academic with albinism from Atlanta, Georgia, also believes that the way you learn about your own albinism is through support and through self growth. Jon only identifies as African American with albinism but stated albinism seldom comes up in conversations. During our conversation, he joked and stated that “people probably don’t mention my albinism because it’s not invisible”. He has Ocular Albinism, also known as OA, and was never taught about albinism, rather he learned about through living with it. He always knew he was different than
the other kids he went to school with and his parents, but he was not taught about what albinism was. He inquired about it as he grew older, as many with albinism do. When he went into depth about how he was not taught about its genetic differences, Jon informed me that certain discussions were never held in his household, and he attributed it to the time period in which he grew up in. He said,

“As you thrive in life, you want to understand why am I generically different and you learn about it yourself. Some of the reading can create low self-esteem. If I went by the readings that I saw every day, it would dampen life…Albinism is a condition that I was never taught about, and I’m 64 years old. It just wasn’t something you talked about and people didn’t know about it 64 years ago so there was no one to teach me about it in preparation for life”.

Jon was not prepared what would later happen to him later in his career which he stated was a result of his albinism. Jon worked in academia and has OA which affected his vision, but did not prevent him from doing his job. His OA also affected his hair and his skin tone. During his application process, he never disclosed that he had albinism (as it was not required nor necessary), nor that he had any impairments which included his vision. He simply stated that he was African American on his application. While at his job, Jon experienced a level of discrimination that resulted in him being released from his position and offered another position at the school he worked for. This was done through him being wrongfully accused of sexual harassment by hugging a subordinate employee. Jon believes he was discriminated against due to his albinism as his employer did not believe he could perform his day to day work tasks due to his albinism, but Jon was able to all of his duties, then they found another reason to terminate him. There was no formal complaint made by the subordinate who received the hug, therefore,
Jon believes this was discrimination on the school’s behalf. During his interview, he stated that people had higher expectations of him due to his albinism, so he believes that they could not find a real reason to release him from his job. Although Jon lost his position, and had to take another job, he did not file a formal report stating discrimination. While albinism should not affect the individual at the workplace, Jon’s experience shows that not everyone is accepting and can even lead to targeting.

For some, the discrimination from albinism is difficult as it is game of “psychological warfare” as Sam described it. From all of my interviews, I believe all of my participants experienced this to an extent. Sam, was not taught about his albinism either, but rather taught about it through the “school of hard knocks”. Sam grew up with a brother and did not notice that they had different skin tones until the age of 4. At this point, he started to compare himself to his older brother and would begin to question himself about his skin tone and why it was different, as he was also had issues regarding race inside and outside of school. The biggest issue Sam remembered is that he was “too white to be black and too black to be white”. This statement is common in the interviews as it references to both the interviewees skin tone and the way in which people believe that those who identify with African American or Black act. Sam experienced this specifically within the Black community due to how race relations are viewed. From our discussion, he found that majority of his discrimination was from the Black community as the community lacked acceptance and the discrimination was hypocritical. My take of this is that many people from the community may not understand albinism, its complexities, and were not as accepting of it due to the visual differences.
The visual differences of albinism may not always be something that causes issues for every individual with albinism, but Sarah, experienced a type of discrimination within the Black community that made her feel unwelcomed which I learned during my final interview. The amount of discrimination and violence that she faced that she faced by the Black community made her believe that she was not welcomed. After her altercations at school, her and her family decided to move to an area where her and family felt there would be a more accepting group of students. The area in which she moved was more welcoming as she explained. Her and her sibling both have albinism, and the area in which she moved was “better suited” for her. Upon transferring into her new school, she felt more welcomed by the Latino community due to her previous experiences. “I didn’t speak Spanish at all, but they taught me. I had to transfer out of my school due to self-defense. The kids at my new school were accepting of my albinism and I was not bullied like I was at my old school”. Sandra understood that she was still Black, but her feelings towards the African American community changed as she felt that their color preferences and her skin color did not align. She informed me that she chose the Latino community as she believed that they did not look at her skin tone, but they only looked at her and her personality. Currently, she is not married to a Hispanic man and her children speak Spanish and identify as Latino. For most, it is not common to identify with a different community as the problem of cultural appropriation can arise. An example of this is Rachael Dolezal, a White woman who decided to self-identify publicly as an African American woman but made profit from it. In this case, she culturally appropriated the African American culture as she exploited it as she moved from a culture that is considered the majority within the U.S. to one that is the Minority for profit. In relation to Sandra, she adopted the Latino culture as she did not feel accepted by those within her race. Sandra, unlike my other participants, does not self-identify
with African American, due to the way she was treated by the community during her childhood. She has a sister that also has albinism who does have albinism that does identify with the African American community, but they did not have the same experience as children in school. Sandra’s albinism affects her eyes and her school gave her access to visual impairment necessities. Sandra and her sister went to the same school and after Sandra’s issue with discrimination and having to defend herself in school which led to her having to transfer, she no longer had access to the visual impairment aids.

5.2 “Albinism is not a Disability; it is a Condition”

Through my interviews, it was a common response that albinism was not a disability and that it was a condition, which is true. Albinism targets the skin, but many do not know how it affects other areas of life as well but it does not hinder individuals. From my interviews, it was apparent that many believed that individuals with albinism were seen as individuals that were not able to perform at their jobs or need extra accommodations that either led to their terminator or discrimination at their current job. While applying to a job, all individuals have to fill out a disability disclosure form. Regardless of the company, all forms are standard, and no form asks if the future employee has albinism.

Following work discrimination, another issue learned from the interviews was that all of my participants were judged based upon their skin tone, rather than their personality and many may treat individuals with albinism differently due to it. When judged due to their skin tone, majority by those within the African American community, it can create a feeling of shame or misunderstanding as all of my participants once identified with this community and later felt as
though this community at one point did not want them due to them not sharing the same appearances.

5.3 Survey Results

The surveys that were conducted for this study were done via Qualtrics and were all done anonymously. Each participant read and electronically signed the form that can be seen in appendix A.1. This survey resulted in 2 males in 3 females. Results are shown below in table 2 and some answers may be shorted in the table and later expanded in this chapter. The results from my surveys fell similar to those of my in-depth interviews.

<table>
<thead>
<tr>
<th>Table 2 Qualtrics Survey Results</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Questions</strong></td>
</tr>
<tr>
<td>1. How old are you?</td>
</tr>
<tr>
<td>Numerical</td>
</tr>
<tr>
<td>2. What is your gender?</td>
</tr>
<tr>
<td>3. Do you have children?</td>
</tr>
<tr>
<td>4. Do you work outdoors (not within an office space)?</td>
</tr>
<tr>
<td>5. Do you self-identify as Albino?</td>
</tr>
<tr>
<td>6. What form of Albinism do you have? OCA or OA?</td>
</tr>
<tr>
<td>7. What is your racial/ethnic identity?</td>
</tr>
<tr>
<td>9. Has albinism hindered you from accomplishing any tasks?</td>
</tr>
<tr>
<td>10. Does having albinism affect how others perceive you in terms of race</td>
</tr>
</tbody>
</table>
or ethnicity? Does this affect your self-perception?

<table>
<thead>
<tr>
<th>Question</th>
<th>Response</th>
</tr>
</thead>
<tbody>
<tr>
<td>11. Do you have to take special precautions in daily life because of albinism? If so, what are they?</td>
<td>4 (80%) yes; 1 (20%) no varying short responses</td>
</tr>
<tr>
<td>12. Have you ever been discriminated against as an individual with albinism? If so, can you please share an experience.</td>
<td>5 (100%) Varying short responses</td>
</tr>
<tr>
<td>13. Does anyone in your family have albinism?</td>
<td>5 (100%)</td>
</tr>
<tr>
<td>14. If you needed support, do you have support system (i.e. friends, family, mentors)?</td>
<td>4 (80%) yes; 1 (20%) maybe</td>
</tr>
</tbody>
</table>

The survey given was solely given to participants over the age of 18 as I wanted to only speak to the participant and not have to compromise any information by going through parent(s) as it could have compromised the information given during the survey from the participant nor did I want to have any ethical issues. From my survey results, I had 2 males and 3 females answer my online survey. The first question in the survey to be interpreted is if my survey participants work outdoors or not. From the results, 5/5 of my participants said that they did not work outdoors. This question was imperative as it was geared to see if individuals with albinism were willing to work in outdoor conditions. With albinism, OCA and OA, working in conditions where an individual can be exposed to high amounts of sunlight can be damaging to the skin and eyes and can cause health issues such as skin cancer or damage to the eyes. Following this, I asked a question that was similar to that of my in-depth interview question, which was if individuals self-identified as albino. The answers from my interviews differed drastically from that of my surveys. My surveys indicated that individuals identified as albino, while my interviews did not as all of my interviewees said they identified with their race rather than their skin condition. I
believe this may be due to the way my question may have been worded. While all participants said they identified as albino, only 4 answered that they have oculocutaneous albinism and 1 has ocular albinism, but from the previous question, all identify with albinism which lead me to believe that all participants skin may be affected by albinism. Later in the survey, question 9 shown in table 2 asks about others and the perception of racial identity and how it may affect ones’ self-perception. All participants agree that others perception does affect their self-identification. One participant explained that “it makes it hard to have courage to trust your ability when people place you in a box based on their limited understanding of albinism…”. As explained in earlier chapters, albinism is not necessarily a disability, but can be debilitating. My survey results reflect that as the majority of answered they believed that albinism is a form of a disability, which can also be seen in table 2. One quote from the answers that that stuck out during the surveys is presented below.

“Low vision associated with Albinism is a disability. People’s negative attitude about the appearance Albinism in the black community is emotionally debilitating. Confrontational, rude, disrespectful, and unnecessary competition from peers can contribute to depression and low self esteem. Lack of acceptance seems to lead to a lot of acting out to fit in from the younger unadjusted Albinism demographic. Ages 32-21 mostly female but some male as well”.

This question can link to the following which is, has albinism hindered the accomplishment of any tasks. Majority answered yes. In both survey and interviews, the results showed that vision was one of the main physical reasons that hindered accomplishing any tasks was visual
impairment that accompanied albinism. I believe that albinism, the skin condition itself, is not a disability as skin tone should never hinder someone from any task. For individuals

6 DISCUSSION AND CONCLUSIONS

6.1 Discussions

I was fairly wary about the interview process as well as gathering photos from my participants. For the interview process, I expected my participants to be highly reserved in the stories they told. For each participant, I truly expected each participant to have less traumatic experiences due to how they have described their family life and the areas in which they grew up in. While I am aware that environment can only shelter one from so much, I did not expect the participants to have the experiences that they did. Many of their experiences were filled with discrimination and hate crimes. These interactions were not only from people who we consider White; the majority were intraracial, which is not expected as I came into this research with expectations of the African American community to accept those with skin variations. For my ethnographic portion, I was unsure that my participants would be comfortable speaking about their skin conditions, as I expected it to be something that they had to speak about often through childhood. Next, I expected to also have more participants than I did for my study, but I ran into the issue of scheduling as some said they would get back to me, but due to scheduling conflict, they were not able to meet or make time for a Skype interview.

My research was based out of Atlanta, Georgia and was conducted both through in-depth interviews over Skype and through an online survey. While I intended to survey and interview participants both in and outside of the state of Georgia, all of my participants were in-state. However, my research was not restricted by this geographic limitation as Atlanta, Georgia is one
of the most culturally diverse cities in the United States. Although I was not able to meet with individuals face-to-face, I was able to contact individuals through the internet for Skype interviews, and surveys were solely done through an online medium. The in-depth interviews each lasted for 1-2 hours and allowed each participants to answer questions that were geared to gather ethnographic insight on how each participant views their albinism. From all of my interviews and surveys, I found that all of my participants experienced a level of discrimination regardless of age or gender. With this research, I had three main key questions. My first was how does an individual with albinism self-identify. This question was particularly difficult to define as albinism is not a race, gender, or sexuality, but it is a way that someone could decide that they could identify with as it is how someone could prefer to set themselves apart or add to their racial identity. My second question was if individuals with albinism have support through their community and/or their family. While it may seem expected that all people have support through their family for any medical condition, this is not always the case as many individuals with albinism that are within the African American community, as I have shown in earlier discussions through my results, have been discriminated against due to albinism. When going into this research, I had expectations of community members to uplift and even take on the responsibilities as mentors for those with albinism, but in certain cases, some stated that there would be issues of competition, discrimination, and even violence within the community towards those with albinism. My final question that aimed to answer was what precautions are taken in terms of daily life, if any were able to be taken at all. This was mainly to see if my participants were taking precautions such as using sunscreen, avoiding areas that were exposed to sunlight, and to see if they worked indoors or outdoors. I also was looking to see if participants took precautions of avoiding certain conversations or even people during daily life, and while I know
this is not an ideal subject to look at, many of my participants did speak about how they believe perceptions of other did change how they viewed themselves.

All of my interviewees discussed how they experienced a level of discrimination due to their skin tone. During half of my interviews, the conversation of discrimination was focused around how majority of the discrimination came from the African American community. With discrimination that happens within the community, it can break trust as all of my participants wanted to be accepted by their community. One question I was compelled to ask but did not feel comfortable was if any of the participants ever asked those within the African American community why they committed any actions towards them that would make them feel like an outcast or make them feel unaccepted. This question is specifically what I would want to see done as further research, as I would like to also see the input of the African American community as a whole.

6.2 Future Research

For future research, I want to continue working with the albino community. Due to some methodological errors I experienced, I was not able to have the full sample size that I expected. In the future, I would like to have 10 or more participants for my in-depth interviews by recreating the way that I contact individuals that I am interested in working with. For initial contact, I would contact individuals who I thought would be interested. To better my chances and increase my participant numbers for future research, I would create a flyer with information where I could be contacted for in-depth interviews as it would allow participants to contact me, rather than me contact them. When I would contact each subject for interviews via email, there
was an issue with communication as most individuals would take a period of days to check their
emails and correspondence would be stagnant. To mitigate the time lapse of correspondence of
recruitment, I believe having a flyer with the information, including my phone number, where
possible participants can contact me and I can build rapport with each one. I believe a phone call
would be more personal, rather than using an email to explain the research, as an email can
appear very systematic to an individual who may not be involved in academia or may even
appear as “spam” mail.

For general future research, I would like to see a cross-comparison done between how
those within the African American community and how they view those within the albino
community. As an anthropologist, it is important to understand both sides. Those from my
research stated that they do not necessarily feel accepted from the African American community.
I would like to see research done on how those within the African American community without
albinism and their perception on albinism and how they feel about acceptance within the African
American community. While these communities are not mutually exclusive, those that have
albinism feel that they are excluded, and I would like to gain perspective from the African
American community as to why or what they believe why certain individuals may cause those
with individuals to be pushed to the periphery of the African American community. With this
future research, I hope it can break down some walls that have been created between these two
communities that have been based upon skin tones. As one of my interviewees, Jon, clearly
stated “Skin does not define you, as it does not define anyone. Your personality is what defines
you and no one can put that in a box or on a census”.
REFERENCES


Cancer in African Albinos, Acta Oncologica, 32:6, 621-622

Clark, Rodney, Norman Anderson, Vernessa Clark, and David Williams. 1999. “Racism As a Stressor for African Americans.”


APPENDICES

Appendix A: IRB

Appendix A.1: Informed Consent Form

Georgia State University
Department of Anthropology
Informed Consent

Title: Albinism in the U.S.: Ethnographic Perspectives
Principal Investigator: Cassandra White
Student Principal Investigator (student PI): Tabitha Green

I. Purpose:
You are being asked to be a part of a research study. The goal of the study is to learn more about how your life experiences with albinism. You are being asked to be a part of this study because you are a person affected by albinism (oculocutaneous or ocular) in the U.S. The study will include a maximum of 60 people. 10 people are being asked to be in this part of the study, which involves an interview. A maximum of 50 will complete an online survey. Being in this interview part of the study will take 1-2 hours of your time on one day.

II. Procedures:
If you choose to be a part of this study, you will be interviewed. The interview will take place at a time and place you and the student PI agree on or on Skype. It will be audio recorded if you agree. There will be a set of questions asked during the interview by the student PI. The interview will take 1-2 hours on one day.

We will also ask if you would be willing to provide a photo of yourself that you choose from an activity that is part of your daily life. You can choose the photo. This is optional. You do not have to provide a photo to be in the study. The purpose of the photo is to help others to understand more about daily life for people with albinism. It can also help normalize the experience of albinism.

III. Risks:
In this study, you will not have any more risks than you would in a normal day of life. If you feel upset or want to talk to someone about the issues that come up in the interview, you may want to contact The National Organization for Albinism and Hypopigmentation (NOAH). They may be reached by phone 800 473-2310 (U.S and Canada) or via email info@albinism.org

IV. Benefits:
Being in this study may benefit you personally. It may help you to think about how albinism has impacted your life as you have navigated through life thus far, and how you view albinism in today’s culture.
Overall we hope to learn more about life in the U.S. for people with albinism. This includes challenges and coping mechanisms.

V. Compensation
For in-person interviews, the student P.I. will provide a drink and a snack.

V. Voluntary Participation and Withdrawal:
Being in this study is voluntary. You do not have to be in this study. If you choose to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop being in the study at any time.

IRB NUMBER: H17-6549
IRB APPROVAL DATE: 08/07/2017
IRB EXPIRATION DATE: 09/09/2018
Appendix A.2: Informed Consent - Survey

Title: Albinism in the U.S.: Ethnographic Perspectives
Principal Investigator: Cassandra White
Student Principal Investigator (student PI): Tabitha Green

I. Purpose:
You are being asked to be a part of a research study. The goal of the study is to learn more about your life experiences with albinism. You are being asked to be a part of this study because you are a person affected by albinism (oculocutaneous or ocular) in the U.S. The study will include a maximum of 60 people. A maximum of 50 people will do the survey part of the study. There is another part of the study in which a maximum of 10 people will do in-depth interviews. This consent form is for the survey part of the study. Doing this part of the study will take about 10 minutes of your time on one day.

II. Procedures:
If you choose to be in this part of the study, you will take part in a survey. The survey will have questions about your daily life with albinism. This survey should only take 10 minutes to do online. After reading this form, you can click “yes” at the bottom if you agree to do the survey. After doing the survey and clicking “submit,” it will be sent to the student PI.

III. Risks:
In this study, you will have no more risks than you would in a normal day of life. If you feel upset or want to talk to someone about things that the survey makes you think about, you can contact The National Organization for Albinism and Hypopigmentation (NOAH). They may be reached by phone 800 473-2310 (US and Canada) or via email info@albinism.org

IV. Benefits:
Being in this study may benefit you personally. It may help you to think about how albinism has impacted your life as you have navigated through life thus far, and how you view albinism in today’s culture. Overall we hope to learn more about life in the U.S. for people with albinism. This includes challenges and coping mechanisms.

V. Voluntary Participation and Withdrawal:
Being in this study is voluntary. You do not have to be in this study. If you choose to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop being in the study at any time.

VI. Confidentiality:
We will keep your records private to the extent allowed by law. We will not ask for your name or identifiable data on the survey. The student PI, Tabitha Green, will have access to the data you give. Data may also be shared with those who make sure the study is done correctly (GSU Institutional Review Board, the Office for Human Research Protection (OHRP). We will not collect your name or identifiable information for this study. The data from your study will be stored on a firewall protected computer. It will be stored on a firewall protected computer. We will use a pseudonym (fake name) to refer to data you include in the survey. Your name and other facts that might point to you will not show up when we present this study or publish its results. You will not be identified personally.
Appendix B – Informed Consent

Title: Albinism in the U.S.: Ethnographic Perspectives
Principal Investigator: Cassandra White
Student Principal Investigator (student PI): Tabitha Green

I. Purpose:
You are being asked to be a part of a research study. The goal of the study is to learn more about how your life experiences with albinism through a quantitative analysis. You are being asked to be a part of this study because you are a person affected by albinism (oculocutaneous or ocular) in the U.S. The study will include a maximum of 50 people. Being in this study will take about 10 minutes of your time on one day.

II. Procedures:
If you choose to be a part of this portion of the study, you will take part in a survey. This survey should only take 10 minutes and should be sent back to the interviewer. After reading this form, you can click “yes” at the bottom if you agree to do the survey.

III. Risks:
In this study, you will not have any more risks than you would in a normal day of life. If you feel upset or want to talk to someone about things that the survey makes you think about, you can contact The National Organization for Albinism and Hyperpigmentation (NOAH). They may be reached by phone 800-473-2310 (US and Canada) or via email info@albinism.org

IV. Benefits:
Being in this study may benefit you personally. It may help you to think about how albinism has impacted your life as you have navigated through life thus far, and now how you view albinism in today’s culture. Overall we hope to learn more about life in the U.S. for people with albinism. This includes challenges and coping mechanisms.

V. Voluntary Participation and Withdrawal:
Being in this study is voluntary. You do not have to be in this study. If you choose to be in the study and change your mind, you have the right to drop out at any time. You may skip questions or stop being in the study at any time.

VI. Confidentiality:
We will keep your records private to the extent allowed by law. We will not ask for your name or identifiable information on the survey. The student PI, Tabitha Green, will have access to the data you provide. Data may also be shared with those who make sure the study is done correctly (DSU Institutional Review Board, the Office for Human Research Protection (OHRP). We will not collect your name or identifiable information for this study. The data from your study will be stored on a firewall protected computer. It will be stored on a firewall protected computer. We will use a pseudonym (like name) to refer to data you include in the survey. Your name and other facts that might point you to will not show up when we present this study or publish its results. You will not be identified personally.

We will make every possible effort to keep your data confidential. Please note that data sent over the internet cannot be guaranteed to be secure. However, Qualtrics encrypts the data that you send, which adds a level of security.

VII. Contact Persons:
Contact Cassandra White at 404-413-5150 or cwhite@gae.edu or Tabitha Green at 404-895-9866 or tgreen32@student.gsu.edu if you have questions, concerns, or complaints about this study. You can also call if you think you have been harmed by the study. Call Susan Bogner in the Georgia State University Office of Research Integrity at 404-413-2513 or sbogner@gsu.edu if you want to talk to someone who is not part of the study team. You can talk about questions or concerns, offer input, get information, or give suggestions about the study. You can also call Susan Bogner if you have questions or concerns about your rights in this study.

VIII. Copy of Consent Form to Participant:
You can print a copy of this consent form to keep.

If you are willing to volunteer for this research and be audio recorded, please click “yes” below.

Please close your browser after doing the survey.
Appendix C – Survey

☐ Q2. By agreeing to participating you are indicating that you are at least 18 years of age and have read the above consent form. If you wish to continue, please select yes.
   √ Yes

☐ Q1. How old are you? (Please type a numerical number)
   [ ]

☐ Q2. What is your gender?
   ☐ Male
   ☐ Female
   ☐ x Trans Male/Trans Man
   ☐ Trans Female/Trans Woman
   ☐ Genderqueer/Gender NonConforming
   ☐ Other

☐ Q3. Do you have any children?
   ☐ Yes
   ☐ No
<table>
<thead>
<tr>
<th>Q4</th>
<th>Do you work outdoor? (Not within an office space)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Yes</td>
</tr>
<tr>
<td></td>
<td>□ No</td>
</tr>
<tr>
<td></td>
<td>□ Partially/Sometimes</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q5</th>
<th>Do you self-identify as Albino?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Yes</td>
</tr>
<tr>
<td></td>
<td>□ No</td>
</tr>
<tr>
<td></td>
<td>□ Sometimes</td>
</tr>
<tr>
<td></td>
<td>□ N/A</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q6</th>
<th>What form of Albinism do you have?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>□ Oculocutaneous Albinism (OCA)</td>
</tr>
<tr>
<td></td>
<td>□ Ocular Albinism (OA)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Q7</th>
<th>What is your racial/ethnic identity?</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Q8</th>
<th>Do you consider albinism a form of disability? If so, why?</th>
</tr>
</thead>
</table>

Q9
Has albinism hindered you from accomplishing any tasks?
- Yes
- No
- Sometimes
- N/A

Q10
Does having albinism affect how others perceive you in terms of race or ethnicity? Does this affect your self-perception? (Please type a short response for this)

Q11
Do you have to take special precautions in daily life because of albinism? If so, what are they? (Please type a short response for this)

Q12
Have you ever been discriminated against as an individual with albinism? If so, can you please share an experience. (Please type a short response for this)

Q13
Does anyone in your family have albinism?
- Yes
- No
- N/A

Q14
If you needed support, do you have a support system (i.e. friends, family, mentors)?
- Yes
- No
- Maybe
- N/A