THE LIVED EXPERIENCES OF PARENTS RAISING A CHILD WITH ALBINISM: A TRANSCENDENTAL PHENOMENOLOGICAL STUDY

by

Quineesha Danyelle Phillips

Liberty University

A Dissertation Presented in Partial Fulfillment
Of the Requirements for the Degree
Doctor of Philosophy

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Abstract

The purpose of this transcendental phenomenological study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. The theory guiding this study was Goffman's social stigma theory on stigmas, as it provides the framework for understanding the educational barriers faced in the general education classroom. This study answers the central research question, what are the lived experiences of parents of children with albinism in school? This transcendental phenomenological study emphasized the need for policy and practice changes focusing on assertiveness and coping skills for students with albinism in primary general education classrooms. The study's sample consisted of eleven participants, all parents of children with OCA. Collected data was triangulated through individual interviews, a focus group session, and a journal prompt. Moustaka's modified Van Kaam (1994) research framework was used to identify and describe the participant's lived experiences of the psychological barriers parents endure while their CWA attends general education. To aid in understanding, an embedded analysis will be used to analyze the data. This study's findings highlighted areas of concern for academic success contributing to CWA's psychological barriers in the general education classroom. The primary finding of this study revealed that parents of CWA in general education classes experience parental challenges in the form of paradox of emotions, interactions with society, and parenting adjustments. Parental challenges are driven by the psychological, educational, and cultural challenges CWA while attending general education classes. This research supported existing literature claiming that albinism is a condition that affects the individual and their family physically, socially, and psychologically.

Keywords: albinism, psychological barriers, stigma, primary school

Copyright Page

Dedication

To my husband, Jeffery; thank you for supporting me through this journey. To my children, Kayson, Sebastian, Teagan, and Bellamy, you are my inspiration for this dissertation and my motivation for everything I do.

Acknowledgments

I want to thank Dr. Darren Howland and Dr. Breck Perry for helping me through this process. I would not have been able to get through this stage of my educational career without your constant support. I would also like to thank my cohort peers for their ongoing support and encouragement when I doubted my abilities. To my previous professors and everyone who has helped me throughout this process, thank you for the opportunity and your unwavering support.

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List of Abbreviations

Applied Behavior Analysis (ABA)

Children with Albinism (CWA)

Every Student Succeeds Act (ESSA)

Individuals with Disabilities Education Act (IDEA)

National Organization for Albinism and Hyperpigmentation (NOAH)

Ocular Albinism (OA)

Oculocutaneous albinism (OCA)

People with Albinism (PWA)

Ultra-violet (UV)

CHAPTER ONE: INTRODUCTION

Overview

Albinism is seen in 1 out of 17,000 people worldwide (Affram et al., 2019). Visible skin conditions, like albinism, affect an individual's quality of life, dependent upon external factors (Anshelevich et al., 2021). Individuals with albinism face difficulties obtaining equal rights to physical, psychosocial, and environmental health and therefore experience a lower quality of life (Anshelevich et al., 2021). The psychosocial health of individuals with albinism is impacted by stigma, discrimination, and myths that create educational barriers. Children with albinism (CWA) experience psychosocial barriers in school during a critical stage when cognitive and social-emotional skills are acquired that will shape their future mental health and success in society (Chetty & Hargovan, 2021; Kromberg, 2018; Melham, 2021). Albinism affects not only the individual but the family as well. This study answers the central research question, what are the lived experiences of parents of children with albinism in school? This transcendental phenomenological study seeks to understand and interpret the psychological barriers CWA parents encounter in the general education classroom. Chapter One presents the background of the ongoing problem caregivers of children with albinism (CWA) face with having little to no resources to help CWA overcome psychological barriers in the general education classroom. The chapter progresses with the purpose of the study, the significance of the study, the research questions, and the definition of critical terms.

Background

Albinism is a genetic condition caused by inherited genes that affect melanin production in the affected individual. There are two main types of albinism, oculocutaneous albinism (OCA), which affects the eyes, skin, and hair, and ocular albinism (OA), which affects the eyes only. Of the two types, OCA is the most common (Affram et al., 2019). Approximately 1 in 37,000 people are born with albinism and, due to their appearance, are the target of many demeaning and cruel acts from society (Affram et al., 2019; Gaigher et al., 2002; Vernon et al., 2021).

People with OCA depict a physical appearance that a strikingly different from that of their peers, characterized by pale skin and hair, light-colored eyes, and nystagmus, which is involuntary rapid eye movement (Affram et al., 2019; Gaigher et al., 2002; Vernon et al., 2021). Studies have shown that negative attitudes toward PWA create significant barriers to well-being and learning (Reimer-Kirkham et al., 2019). Albinism has challenges intrinsically; however, when coupled with skewed societal norms, the challenges become educational barriers.

Historical Context

The first accounting of a PWA was in the first century A.D. from Pliny, who described some Albanian men as those with sea-green color eyes, white hair, and could see better at night (Kromberg, 2018). Throughout history, accountings of albinism appear amongst several pieces of literature along with the misconceptions of albinism. In 1688, accounts of “albinos” referred to them as deformed and a loss of posterity (Kromberg, 2018). PWA was often thought to be the result of infidelity, the work of the devil, or a blessing from the Gods, often shunned by their families, killed, or worshipped in many parts (Kromberg, 2018). It was not until 1908 when British physician Archibald Edward Garrod discovered that albinism was an inherited disease caused by a genetic mutation (Knox, 1958). Despite this discovery, cultures worldwide developed myths and superstitions of PWA that are present currently, such as people with albinism are thought to have magical powers, have an intellectual disability, and albinism is contagious (Chu, 2015). Research has shown that many of these superstitions and myths are generated in African countries (Affram et al., 2019; Vernon et al., 2021). The variations in the treatment of PWA in Africa vary from violence against, attacks, or killing of PWA (Affram et al., 2019; Vernon et al., 2021). Baker, Lund, Nyathi, and Taylor (2010) described instances where PWA in South Africa and Zimbabwe were killed or left to die by their families because of the social stigma associated with their condition. In Zimbabwe, PWA was viewed as belonging to a magical world capable of doing good or evil (Vernon et al., 2021). In Tanzania, PWA is attacked for their body parts, believed to have the potential to access spiritual realms, conjure good fortunes, and prepare magical potions to ward off misfortunes (Vernon et al., 2021).

These misconceptions are also present in the media, where people with albinism are represented as mean, deceitful, evil characters with red eyes (Mswela, 2013). Movies such as The Da Vinci Code, Matrix Reloaded, Powder, and television shows such as Black Lightning depict PWA as either evil, a freak, or the subject of ridicule (Mswela, 2013). The reasoning behind using PWA as the villain results from no balance between the number of villains and the lack of realistic and sympathetic characters in movies (Mswela, 2013). The lack of balance and the presence of myths and subliminal messages from the media influence how society views PWA, leading to discrimination and stigmatization that affects their life educationally and socially.

Social Context

The effects of albinism affect not only the individual but the family as well. Misunderstandings of the cause of albinism add extra family stress, resulting in changes in family dynamics (Brilliant, 2015). Often the mother of an albino child is abandoned by the husband and family out of accusations of infidelity. If the father does stay, CWA is treated harshly. Family members of a PWA must learn to adapt and cope with how society treats loved ones. With the help of a supportive family, a child with albinism can learn to adjust and feel accepted by the family but often faces stigmatization from society (Kromberg, 2018). Stigmatization from the community manifests as educational barriers and can damage the individual and their family (Tambala-Kaliati, 2020). CWA can be the target of many harsh and damaging acts. Therefore, aside from parents, teachers play an important role in the lives of CWA. Teachers are responsible for helping a child with albinism learn and realize his or her potential in life (Ashley, 1992). Students with albinism have experienced stigmatization that has long-lasting effects including a lack of confidence and self-esteem (Tambala-Kaliati, 2020). As a result, CWA are denied the ability to learn and develop as individuals (Aborisade, 2022; Affram et al., 2019; Chetty & Hargovan, 2021; Corn & Lusk, 2018a; Corn & Lusk, 2018b). It is important to be accommodating to the needs of CWA. In addition to visual impairment needs, CWA also need love and respect shown to them to build self-esteem and confidence (Darling-Hammond & Cook-Harvey, 2018). How a teacher responds to students with albinism influences how other students respond and affects the educational environment and achievement of children with albinism (Darling-Hammond & Cook-Harvey, 2018). Therefore, this study will aid in the understanding of the social context that parents and caregivers endure when caring for a CWA and help teachers understand the support needs of students with albinism. This study will depict the lived experiences of those caring for CWA and how societal stigmatization affects home and school life.

Theoretical Context

The stigmatization of PWA has been well-researched, showing evidence of stigmatization, discrimination, and violation of human rights. In Uganda, most Ugandans fear PWA by viewing them with suspicion and believe PWA possess supernatural powers because of the beliefs, myths, traditions, and attitudes surrounding people with albinism (Bradbury-Jones et al., 2018). PWA also experience a cascading effect from stigmatization that affected their academic attainment, which affected employability, leading to financial difficulties that ultimately affected the ability to obtain adequate health care for the skin and eyes (Tambala-Kaliati, 2020). In the school setting, learners with albinism are often isolated from activities that stimulate cognitive and perceptual-motor development because they cannot participate in outdoor activities and tasks (Gaigher et al., 2002). Social exclusion can be a significant barrier to learning and the general well-being of learners with albinism (Reimer-Kirkham et al., 2019; Vernon et al., 2019).

Due to the high number of PWA in Africa, efforts have been made to reduce the stigmatization of PWA using two radio interventions that allowed contact with PWA (de Groot et al., 2022). By enabling anonymous connection with PWA, there was a significant reduction in community stigma, increased knowledge, and attitude toward PWA, and reduced social distance. De Groot's (2022) study and similar present the aspects surrounding albinism involving stigmatization and how society can elicit change.

Changes in society will also need to be on an educational level if a PWA is to overcome the academic barriers. "Children with albinism, especially those of African American, Asian and Latin decent, have a dramatic physical appearance which could cause other children to tease or say unkind things" (Ashley, 1992, p. 9). However, proactively addressing the issue calls for a change in the environment in which CWA is placed. CWA is placed in classrooms with peers with a bad attitude towards PWA that stems from a lack of knowledge about albinism which leads to alienation (Reimer-Kirkham et al., 2019; Vernon et al., 2019). As a result, CWA faced social problems such as name-calling, ridicule, and peer violence (Lund, 2001; Reimer-Kirkham et al., 2019; Vernon et al., 2019). Negative experiences in elementary school can have a lasting affect on children at a stage where the need for physical expression of love and care (Vernon et al., 2019). It is when there is an understanding of the disability, is when teasing stops (Ashley, 1992). However, stopping teasing is only half the problem; the other is teacher preparation. Research shows that CWA teachers are inadequate to support (Lynch et al., 2014; Reimer-Kirkham et al., 2019; Vernon et al., 2019). During pre-service training, teachers reported taking a special education course; however, many had little knowledge of supporting visually impaired learners (Lynch et al., 2014; Reimer-Kirkham et al., 2019; Vernon et al., 2019). Teachers lack knowledge on how to help CWA aid in the discrimination and barriers to education in the general education classroom by placing them in situations not conducive to learning, such as the back of the classroom, calling them out to read something from far away, not allowing them to move close to the board or bringing attention to them when needing to come to the front of the class (Lynch et al., 2014; Reimer-Kirkham et al., 2019; Vernon et al., 2019). To combat barriers to education, changes to policies and practices in the pre-service curriculum, professional development of current teachers, and procedures must be put in place in the educational system that furthers the teachings of inclusive teaching to overcome the psychological barriers to education PWA face (Lynch et al., 2014; Reimer-Kirkham et al., 2019; Vernon et al., 2019).

Problem Statement

The problem is that PWA face societal stigmatization which manifests in educational barriers. Psychological barriers, coupled with a lack of adequate teacher training and practices available to assist children with albinism in the general education classroom, create a melting pot for barriers to education. Caregivers of children with albinism (CWA) have little to no resources to help CWA overcome psychological barriers in the general education classroom.

Albinism is a genetic condition that results in a lack of pigmentation. There are two types of albinism, each with different sub-types: ocular albinism (OA), which affects the eyes but not the skin or hair, and oculocutaneous albinism (OCA), which results in lack of pigmentation of the hair, skin, and eyes. For this study, the focus will be on those affected by oculocutaneous albinism.

PWA face societal stigmatization, which manifests into educational barriers (Vernon et al., 2021). Due to stigmas placed upon PWA, individuals are often shunned, deemed unworthy of education, bullied, discriminated against, and attacked (Affram et al., 2019). When these stigmas begin to affect educational attainment, it has been shown to affect finances, which leads to deficits in access to adequate healthcare and can limit the quality of life (Tambala-Kaliati, 2020).

Purpose Statement

The purpose of this transcendental phenomenological study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. At this stage in the research, psychological barriers will be generally defined as a person's state of mind that can limit their ability to make the right decisions (Olson, 1992). The theory guiding this study is Ervin Goffman's stigma theory. The current teacher education curriculum includes a brief course in special education with no emphasis on assisting students with albinism. Veteran teachers need to learn how to help students with albinism due to not being special education teachers. Given the rarity of albinism, research focuses on the barriers and physical accommodations that can be made; however, there is not much research focusing on the psychological barriers.

Significance of the Study

The feeling of not belonging is familiar amongst PWA and is the direct result of stigmatization and discrimination (Aborisade, 2021; Anshelevich, 2021; Bradbury-Jones et al., 2018; Brocco, 2016; Kromberg, 2018; Marcon & Maia, 2019). Globally, PWA is marginalized and has limited social and medical support due to the misunderstanding of albinism (Brocco, 2016; Kiluwa et al., 2022; Maunganidze et al., 2022). Appropriate social and medical support for PWA is essential; therefore, this section explains how this study will contribute to the knowledge base of the lived experiences of caregivers of CWA from a theoretical, empirical, and practical perspective.

Theoretical

Given the importance of education and the relationship between psychological barriers and education attainment for PWA, a social constructivist perspective allows for a better understanding of how human development is socially centered. Within the social constructivist perspective, successful teaching and learning depend on interpersonal interactions (Darling-Hammond & Cook-Harvey, 2018). The relationship between exchanges in the general education classroom between PWA and their peers significantly affects their educational attainment; when that interaction is negative, it can reduce academic success (Affram et al., 2019). The relationship between negative interactions and individual behavior is reflected in Erwin Goffman’s (2009) theory of social stigma. This research study will contribute to theoretical underpinnings of Goffman’s (2009) theory of social stigma by understanding how stigmas are internalized and inadvertently shape individual behavior of CWA in general education classrooms. The utilization of a social constructivist perspective for this transcendental phenomenological study will further provide an interpretation of the lived experiences of caregivers of CWA in general education classrooms across the United States.

Empirical

By looking at the lived experiences of parents of children with albinism and identifying emerging themes, school administrators or stakeholders will be able to increase knowledge of albinism and identify areas of needed change withing the school system to improve awareness of albinism in the educational setting. The stigmatization of PWA has been well-researched, showing evidence of stigmatization, discrimination, and violation of human rights (Aborisade, 2022). Social exclusion can be a significant barrier to learning and the general well-being of learners with albinism (Reimer-Kirkham et al., 2019). Teachers of CWA are inadequate in their ability to support the needs of CWA and aid in stigmatization (Reimer-Kirkham et al., 2019). The current research surrounding albinism looks at the physical barriers; this study will look at how psychological barriers affect home and education. Data gathered from this study will provide an understanding of the lived experiences of parents of children with albinism, which can be used to elicit change in school administrators or stakeholders to improve knowledge and awareness of albinism in the educational setting.

Practical

This study will provide the lived experiences of caregivers of CWA as they access the general education classroom. The study focuses on the psychological barriers caregivers deal with as CWA attend public school. Classrooms are becoming more diverse as more school systems push toward inclusive teaching (Chetty & Hargovan, 2021). Thus, more students with disabilities are placed in the least restrictive environment with unequipped teachers (Corn & Husk, 2018a). This study will provide information that can be shared with other parents, teachers, and administrators to help classrooms become more inclusive for those with albinism by addressing the psychological barriers in general education classrooms.

Research Questions

In alignment with the relationship between stigmatization and how detrimental they are for PWA, the proposed research questions for this study will center around Goffman's social stigma theory to better understand the essence of a parent's experience of raising a child with albinism, followed by sub research questions that look at each identified stigma of the social stigma theory.

Central Research Question

What are the lived experiences of parents of children with albinism in school?

Sub-Question One

What affect does albinism have on a person's character/mentality in school?

Sub-Question Two

What affect does albinism have on a person physically in education?

Sub-Question Three

What affect does albinism have on a person's ability to identify with a particular group/race/religion?

Definitions

1. *Albinism*–a genetic condition characterized by variable degrees of hypopigmentation and ophthalmological anomalies (Arveiler, 2019)
2. *Astigmatism*-an imperfection in the eye's curvature resulting in distorted images as light rays are prevented from meeting at a common focus (Reimer-Kirkham et al., 2019)
3. *Certified teacher*- an educator who has earned credentials from an authoritative source (Andersson et al., 2011)

4. *Contrast sensitivity*- the difference in brightness between a target and its background (Jhetam & Mashige, 2019)
5. *Differentiated instruction*-an approach where teachers adjust their method of delivery to maximize learning for all students (Kiramba et al., 2022)
6. *General education*- a classroom that is composed of students of who at least 70% are without identified special education disability (Parey, 2019)
7. *Hypopigmentation*-lack of pigmentation in the skin (Arveiler et al., 2020)
8. *Inclusive education*- all students being able to access and gain equal opportunities for education and learning (Parey, 2019)
9. *Least restrictive environment*- a child with a disability is educated with non-disabled peers as much as possible (Parey, 2019)
10. *Malignant*-grow and spread to other parts of the body (Marcon & Maia, 2019)
11. *Melanin*-pigment occurring in the hair, skin, and iris of the eye (Marcon & Maia, 2019)
12. *Melanocytes*-a cell in the body that produces and contains the pigment melanin (Marcon & Maia, 2019)
13. *Morbidity*- the condition of suffering from a disease (Marcon & Maia, 2019)
14. *Mortality*-death (Marcon & Maia, 2019)
15. *Null point*-one place where the eyes stop moving (Casteels et al., 1992)
16. *Nystagmus*- the rapid, involuntary shaking movement of the eyes (Casteels et al., 1992)
17. *Ocular Albinism*-inherited genetic disorder that results in decreased pigment in the eyes (Casteels et al., 1992)
18. *Oculocutaneous Albinism*- an inherited genetic disorder that results in decreased pigment in the hair, skin, and eyes (Casteels et al., 1992)

19. *People first language*- identify the person first, rather than their disability or impairment (Crocker & Smith, 2019)
20. *Photophobia*- sensitivity to bright light and glare (Marcon & Maia, 2019)
21. *Pre-service teacher* – student teachers who are enrolled in a teacher education program and working toward teacher certification (Ambrosetti & Dekkers, 2010)
22. *Professional development*- ongoing learning opportunities available to teachers and other education personnel (Ambrosetti & Dekkers, 2010)
23. *Recessive*- a trait that is expressed only when both pairs of a gene are abnormal (Marcon &Maia, 2019)
24. *Strabismus*-misalignment of the eyes (Yasar, 2022)
25. *Stigma* – an attribute that is deeply discrediting (Goffman, 2009).
26. *Translucent Iris*- little to no pigment to screen out stray light coming into the eye (Gronskov et al., 2007)
27. *Veteran teacher*- who has taught for more years, at least more than three years (Ambrosetti & Dekkers, 2010)
28. *Visual Acuity*-sharpness of vision (Naiman & Azaliwa, 2021)
29. *X-linked*- the gene causing a particular trait is located on the X chromosome (Marcon & Maia, 2019)

Summary

The problem is PWA faces societal stigmatization, which manifests in educational barriers. Psychological barriers, coupled with a lack of adequate teacher training and practices available to assist children with albinism in the general education classroom, create a melting pot for barriers to education (Vernon et al., 2021). Research has shown that ways to overcome stigmas surrounding albinism are to change the course of thinking and improve understanding to overcome societies' myths and superstitions. Therefore, by understanding the lived experiences of parents of children with albinism, data provided from this research can be used to elicit change in school administrators or stakeholders to improve knowledge and awareness of albinism in the educational setting.

CHAPTER TWO: LITERATURE REVIEW

Overview

A systematic literature review about teaching children with albinism (CWA) explores the educational barriers in general education classrooms. This chapter contains a review of the current literature on this topic. The first section will discuss Ervin Goffman's (1963) stigma model as it provides the framework for understanding this topic, followed by a review of recent literature regarding the background of albinism, physical barriers, and psychological barriers to education CWA face. Lastly, a gap in the literature shows a need for more research on addressing the psychological barriers CWA faces.

Theoretical Framework

Stigma originated from the Greeks to describe something or someone's unusual or bad moral status (Goffman, 2009). Over time, the term stigma has been altered in terms of definition and concept. Christians added bodily signs of grace and medical allusions for physical discrepancies; however, today, the term stigma is used close to the original term with more emphasis on disgrace (Goffman, 2009). Goffman (2009) stated, "When a stranger is in front of us, we lean on anticipations, transforming them into normative expectations and righteous requested demands. It is not until we actively question whether these demands are fulfilled that leads to the characterization of social identity" (p. 10). A person's character or attributes are evident when presented; however, when there is a deviation from the expected identity, is when a person is deduced from a whole person to one that is tainted and discounted, a stigma (Goffman, 2009). Goffman (2009) presented three stigmas associated with a stigmatized person: the stigma of character, physical stigma, and group identity (Brocco, 2016; Gaigher et al., 2002; Kleinman & Hall-Clifford, 2019; Link & Phelan, 2001). The stigma model states that stigmas of character, physical, and group identity contribute to an individual’s disqualification from full social acceptance (Goffman, 2009). Goffman noted that “normal” or those without a stigma believe those with a stigma are not human, which leads to discrimination and inferiority. Thus, this way of thinking creates feelings of animosity, derogatory metaphors, and imagery in combination with the original meaning of the term stigma. Once an individual is stigmatized, it negatively affects their life in several ways, such as barriers to education and low social well-being (Affram et al., 2019; Chetty & Hargovan, 2021; Evance & Penda, 2018; Goffman, 2009; Naiman & Azaliwa, 2021; Reimer-Kirkham et al., 2019; Vernon et al., 2021).

Drawing from the original definition, Goffman's (2009) theory of social stigma defines a stigma as an attitude or behavior that is profoundly discrediting in a particular way. For an individual to have a working consensus with others, there must be a mutual acceptance of identities (Chetty & Hargovan, 2021; Kleinman & Hall-Clifford, 2009). Goffman’s stigma theory is guided by the problem of temporary discrepancies in identity (Chetty & Hargovan, 2021; Kleinman & Hall-Clifford, 2009). This working consensus is sometimes unobtainable for PWA due to their physical appearance.

As aforementioned, Goffman (2009) noted three stigmas; the first is the stigma of character, where individuals are stigmatized due to character flaws considered weak, such as low self-esteem, self-worth, depression, or aggression. Goffman’s discussion of stigmas created an understanding of how stigmas are internalized and shape individual behavior. The stigma of character explains how PWA is stigmatized and perceived as weak-willed, unnatural, and lacking in worth (Affram et al., 2019; Chetty & Hargovan, 2021; Kromberg, 2018). The social stigmas surrounding albinism are associated with negative consequences such as enacted, felt, and internalized stigmas (Affram et al., 2019; Chetty & Hargovan, 2021). Internalized stigmas give rise to self-stigmatization, leading to low psychological well-being and life satisfaction (Affram et al., 2019; Chetty & Hargovan, 2021; Kromberg, 2018; Luck-Sikorski et al., 2022; Reimer-Kirkham et al., 2019).

Physical stigma is stigmatizing individuals based on physical deformities such as lacking pigmentation or visual impairment (Goffman, 2009). For PWA, the color of their skin depicts imagery that is different from standard expectations. When this happens, PWA is deduced down from a whole person to one that is tainted and discounted, resulting in being labeled as a stigma (Goffman, 2009).

Group identity stigmas, where individuals have problems identifying with a particular group, are transmitted through lineages and contaminate all family members (Goffman, 2009). Stigmatized individuals do not have full acceptance from society and, in turn, are constantly adjusting their social identities to fit into social norms (Goffman, 2009). PWA face frequent challenges throughout life regarding identity and belonging to a particular group (Kromberg, 2018; Vernon et al., 2021). Identity formation begins in the formative years and continues throughout one’s life as one undergoes different aspects and experiences in a lifetime (Chetty & Hargovan, 2021; Vernon et al., 2021). PWA's experiences are affected by stigmas, discrimination, rumors, inequality, and inferiority, affecting one's identity (Chetty & Hargovan, 2021; Kleinman & Hall-Clifford, 2009; Vernon et al., 2021). During early childhood, one’s identity is formed, which occurs during interactions in school (Chetty & Hargovan, 2021; Vernon et al., 2021). PWA often have a tough time assimilating with society due to the stigmas associated with albinism. Research shows that acceptance by one's community is vital for a well-adjusted life; however, for many with albinism, isolation can negatively impact the development of self and lead to emotional and behavioral problems (Chetty & Hargovan, 2021; Goffman, 2009; Kromberg, 2018; Vernon et al., 2021).

Goffman's identified stigmas depict the challenges PWA face during their formative years that affect them in the classroom (Chetty & Hargovan, 2021; Vernon et al., 2021). Using Goffman's (2009) stigma theory as the framework to guide the phenomenological study will allow for understanding the lived experiences of parents of children with albinism and identifying ways to address the psychological barriers adequately. In turn, the lived experiences of caregivers of CWA can help researchers and educational stakeholders find a way to support CWA sufficiently in an inclusive setting.

Related Literature

The literature surrounding CWA in schools has shown two common themes-of experiences PWA face and the barriers, either physical or psychological (Affram et al., 2019; Evance & Penda, 2018; Kasamba, 2021; Mtonga et al., 2021; Vernon et al., 2021). PWA faces an abundance of challenges in everyday life. However, CWA faces these challenges in addition to regular developmental milestones. When coupled together, these challenges can help or hinder development. Currently, research on albinism explores the experiences of PWA in different countries in Africa, the experiences of women, and how to overcome physical barriers. There needs to be more research on how to adequately support PWA and help overcome the psychological barriers in education. The current literature shows that the most common barrier to education for PWA is physical, although many researchers say the psychological barriers cause more damage (Aborisade, 2022; Affram et al., 2019; Brocco, 2016; Chetty& Hargovan, 2021; Dapi et al., 2018; Evance & Penda, 2018; Naiman & Azaliwa, 2021; Vernon et al., 2021). Psychological barriers create trauma that affects many aspects of an individual's life that spans throughout their lifetime (Aborisade, 2022; Brocco, 2016; Chetty & Hargovan, 2021; Dapi et al., 2018; Estrada-Hernandez, 2018; Kiluwa et al., 2022; Kromberg, 2018; Marcon & Maia, 2019; Maunganidze et al., 2022; Reimer-Kirkham et al., 2019).

Albinism

Albinism is a rare recessive genetic disorder caused by the complete absence or reduction in melanin production in melanocytes, resulting in light-colored hair, skin, and eyes (Arveiler et al., 2020; Bashour, 2020; Brilliant, 2015; Brocco, 2016; Kiluwa et al., 2022; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). For a person to be born with albinism, both parents must be carriers to have a child with albinism (Arveiler et al., 2020; Bashour, 2020; Brilliant, 2015; Brocco, 2016; Kiluwa et al., 2022; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). Just because both parents are carriers does not mean the parents will automatically have a child with albinism. With genetics, there is a 25% chance that parents will have a child with albinism.

When a person is born with albinism, a defect in the gene affects the production of melanin, a substance in the skin that gives skin its pigmentation. Melanin has ultraviolet (UV) absorbent properties to protect skin and eyes from ultraviolet light. Without melanin or a reduction in melanin leads to high susceptibility to skin cancer (Elyas & Bradley, 2021; Federico & Krishnamurthy, 2022; Liu et al., 2021). Along with increased risk of skin cancer, albinism also causes visual impairments such as abnormalities of the retina, astigmatism, translucent iris, nystagmus, strabismus, contrast sensitivity, reduced reading rate, photophobia, and decreased visual acuity (Arveiler et al., 2020; Bashour, 2020; Brilliant, 2015; Brocco, 2016; Gronskov et al., 2007; Marcon & Maia, 2019).

Albinism is present within all ethnic groups with broad phenotypic variability (Arveiler et al., 2020; Bashour, 2020; Brocco, 2016; Marçon & Maia, 2019). The condition can occur in one of two types: ocular albinism type 1 (OA1) or oculocutaneous albinism (OCA) (Arveiler et al., 2020; Bashour, 2020; Brilliant, 2015; Brocco, 2016; Gronskov et al., 2007; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). OA1 is an x-linked recessive disorder and is more commonly found in males. OA1 is an exclusively ocular disorder with varying vision from near normal to legally blind with normal pigmentation to skin and hair (Bashour, 2020; Marcon & Maia, 2019; Gronskov et al., 2007). OCA is more typical of the two and affects both males and females. The OCA clinical spectrum varies with four subtypes with unique phenotypic characteristics (Bashour, 2020; Brilliant, 2015; Brocco, 2016; Gaigher et al., 2002; Gronskov et al., 2007).

For this study, the focus is placed on the more commonly known form of albinism, which is OCA. OCA can occur as one of four subtypes: OCA1, OCA2, OCA3, and OCA4 (Bashour, 2020; Brilliant, 2015; Brocco, 2016; Gaigher et al., 2002; Gronskov et al., 2007). OCA1 has two types (A and B), with OCA1A type the most severe due to the total absence of melanin production; milder forms (OCA1B, OCA2, OCA3, and OCA4) show some pigment accumulation over time (Bashour, 2020; Gronskov et al., 2007; Marcon & Maia, 2019). Approximately one in 17,000 people have one of the types of albinism, with prevalence rates varying worldwide (Bashour, 2020; Kiluwa et al., 2022; Marcon & Maia, 2019). In the US, the prevalence is 1:37,000, while prevalence rates are higher in other regions at 1:20,000 (Bashour, 2020; Brilliant, 2015; Brocco, 2016; Kiluwa et al., 2022; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). However, in Africa, particularly Tanzania, the prevalence of albinism is 1:142 (Bashour, 2020; Brilliant, 2015; Brocco, 2016; Kiluwa et al., 2022; Marcon & Maia, 2019).

OCA1 is the most found subtype in Caucasians, making up more than fifty percent of the cases worldwide (Bashour, 2020; Chetty & Hargovan, 2021; Marçon & Maia, 2019; Reimer-Kirkham et al., 2019). OCA2 is more common in those of African descent, accounting for thirty percent of the cases worldwide (Bashour, 2020; Marçon & Maia, 2019; Reimer-Kirkham et al., 2019). OCA3 is nonexistent in Caucasians but is found globally in 3% of cases (Bashour, 2020; Chetty & Hargovan, 2021; Marçon & Maia, 2019; Reimer-Kirkham et al., 2019). OCA4 is rare in Caucasians and Africans but accounts for seventeen percent of the cases worldwide in Japanese and Chinese backgrounds (Bashour, 2020; Marçon & Maia, 2019; Reimer-Kirkham et al., 2019). All subtypes have similar ocular impairments with varying hypopigmentation.

Physical Barriers

Albinism has inherent physical barriers that vary depending on the affected individual's subtype (Affram et al.,2019; Arveiler et al., 2020; Marcon & Maia, 2019; Naiman & Azaliwa, 2021; Vernon et al., 2021). No matter the subtype, all have contrast sensitivity, astigmatism, translucent iris, photophobia, nystagmus, and strabismus, with varying degrees of reduced visual acuity (Bashour, 2020; Brocco, 2016; Jhetam & Mashige, 2019; Marcon & Maia, 2019). Of the four subtypes, OCA1A is the most severe. OCA1A is distinguished by white hair, eyelashes, and skin, fully translucent light blue to pink irises, extremely low visual acuity, and intense photophobia (Bashour, 2020; Brocco, 2016; Jhetam & Mashige, 2019; Marcon & Maia, 2019). An individual's skin affected by OCA1A will never produce any melanin, leaving their skin unprotected from the sun's harmful rays (Bashour, 2020). OCA2 is characterized by varying reduced skin pigment and iris color and better visual acuity (Bashour, 2020; Brocco, 2016; Jhetam & Mashige, 2019; Marcon & Maia, 2019). OCA3 is characterized by red hair and reddish-brown skin (Bashour, 2020; Brocco, 2016; Jhetam & Mashige, 2019; Marcon & Maia, 2019). OCA4 cannot be clinically distinguished from OCA2 (Bashour, 2020; Brillant, 2015;

Brocco, 2016; Jhetam & Mashige, 2019; Marcon & Maia, 2019). Management of the visual impairment includes corrective lenses and possible bifocals, which provide significant help in improving visual acuity, astigmatism, strabismus, contrast sensitivity, and nystagmus (Bashour, 2020; Brillant, 2015; Brocco, 2016; Gronskov, 2007; Jhetam & Mashige, 2019; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). For photophobia, using transition lenses or dark sunglasses has been shown to lessen the effect when transitioning from outside/to inside (Jhetam & Mashige, 2019; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). Many CWA may utilize a null point, which is the positioning of the head in specific ways to dampen the nystagmus (Bashour, 2020; Brillant, 2015; Brocco, 2016; Gronskov, 2007; Jhetam & Mashige, 2019; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). Aside from the inherent barriers that come with albinism, there are also physical barriers in the school setting that affect CWA (Affram et al., 2019; Kasamba, 2021; Vernon et al., 2021).

Education

Children with albinism should be given special attention at school to manage their visual impairments by using high contrast written materials, more prominent print textbooks, various optic devices to enlarge print, audio readers, and touchscreen laptops with larger screens (Bashour, 2020; Chetty & Hargovan, 2021; Gronskov et al., 2007; Kasamba, 2021; Mtonga et al., 2021; Vernon et al., 2021). With adequate knowledge and an understanding of their unique needs, teachers can help CWA enjoy school and learn normally (Bashour, 2020; Gronskov et al., 2007; Kasamba, 2021; Mtonga et al., 2021; Vernon et al., 2021). However, many teachers and school members often need clarification about supporting CWA; therefore, CWA finds school unpleasant. Many CWA need to receive the required accommodations to help them in the general education classroom (Chetty & Hargovan, 2021; Corn & Lusk, 2018a; Corn & Lusk, 2018b).

Many school systems, specifically those in many African countries, seek to find the best school system for learners with albinism. Physical barriers to education for CWA include loud classrooms that are poorly lit or inadequately supplied with blinds or curtains to block out filtering light that causes eye pain due to light sensitivity, “normal” size font that makes it difficult for CWA to read, and participate in class assignments, teacher’s lack of supplying accommodations, little to no access to necessary assistive technology, and insufficient accessibility of school grounds (Affram et al., 2019; Anshelevich et al., 2021; Kasamba, 2021; Miyauchi & Paul, 2020; Opie, 2018; Vernon et al., 2021). CWA faces these physical barriers because many are educated in classrooms alongside peers without albinism because of inclusive teaching (Lipkin & Okamoto, 2015; Kasamba, 2021; Mtonga et al., 2021; Vernon et al., 2021).

Moreover, school systems are not equipped to provide the needed services for CWA appropriately, given that albinism is a rare genetic condition that affects every 1 in 40,000 individuals (Arveiler et al., 2020; Corn & Lusk, 2018a; Corn & Lusk, 2018b). In attempts to combat many physical barriers, some countries support children with albinism either in mainstream schools or a special school for visual impairments (Gaigher et al., 2002; Mtonga & Chipili, 2016; Mtonga et al., 2021). One such country is Tanzania, with the highest prevalence of PWA at 1:142. Governmental officials in the Limpopo province seek to help CWA at a special school for deaf and blind students. CWA is placed in classes with students who are blind and deaf, leaving them susceptible to hostile treatment from peers out of fear, trouble with academics due to poor eyesight, which makes it challenging to decipher numbers and figures, and inadequately trained teachers (Gaigher et al., 2002; Mtonga & Chipili, 2016; Mtonga et al., 2021). Despite Tanzania’s high prevalence, school officials are still not adequately supporting CWA (Brillant, 2015; Brocco, 2016; Chetty & Hargovan, 2021; de Groot et al., 2020; Gaigher et al., 2002; Kerr et al., 2020; Miyauchi & Paul, 2020; Mtonga et al., 2021). In the United States of America, school systems usually group CWA with those who have visual impairments only or are blind; however, those with albinism are neither (Naiman & Azaliwa, 2021; Vernon et al., 2021; Yasar, 2022).

Like Tanzania, Zambian officials are also looking to support CWA in special schools to help overcome barriers to education. CWA in mainstream schools is harassed by teachers, ridiculed, isolated, placed in situations with poorly trained teachers, and subject to harsh language from teachers and peers (Chetty & Hargovan, 2021; de Groot et al., 2020; Kerr et al., 2020; Mtonga et al., 2021; Mtonga & Chipili, 2016). In special schools, CWAs are welcomed and have a positive learning experience because CWA is given a high level of care and taught by knowledgeable teachers (Mtonga et al., 2021; Mtonga & Chipili, 2016). Some, such as Kabwe and Mandyata (2020), view educating CWA in special schools negatively, stating that CWA could learn in regular schools with their non-disabled peers if CWA were provided with the appropriate materials for their learning.

In an ideal situation, CWA would have a general education teacher and special education teacher knowledgeable of albinism and can help support them in the classroom. This is not the case for many school systems that have unique learners such as those with albinism (Chetty & Hargovan, 2021; Corn & Lusk, 2018a; Kasamba, 2021; Mtonga et al., 2021; Mtonga & Chipili, 2016; Opie, 2018; Opie et al., 2017; Vernon et al., 2021). Due to the lack of appropriate accommodations available to CWA, many can need academic help (Chetty & Hargovan, 2021; Kasamba, 2021; Mtonga et al., 2021; Vernon et al., 2021). Even though reasonable accommodations are required by law, in many countries, such as Europe and Asia, CWA does not receive these supports (Chetty & Hargovan, 2021; Corn & Lusk, 2018a; Kasamba, 2021; Mtonga et al., 2021; Vernon et al., 2021). In the United Kingdom and Ireland, to get relevant support, CWA's parents must navigate an educational tribunal system that rarely provides any support, leaving them to perform poorly in academics (Chetty & Hargovan, 2021). In Ecuador, disability laws only recognize people who are blind, not those with low vision (Chetty & Hargovan, 2021). Aside from visual impairments, CWA also have skin sensitivity issues that affect them educationally (Affram et al., 2019; Kasamba, 2021; Vernon et al., 2021).

Recreational Activities

Albinism affects the production of melanin; without melanin, PWA is predisposed to specific health conditions that include skin cancer (Bashour, 2020; Brillant, 2015; Brocco, 2016; Gronskov et al., 2007; Jhetam & Mashige, 2019; Kerr et al., 2020; Kiluwa et al., 2022; Kromberg, 2018; Marcon et al., 2019; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019; Suh, 2019). For CWA, those with the more severe forms of OCA have little to no pigment; therefore, CWA cannot tan and are easily sunburned (Bashour, 2020; Jhetam & Mashige, 2019; Kerr et al., 2020; Kiluwa et al., 2022; Kromberg, 2018; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019; Suh, 2019). The incidence of skin cancer is increased in CWA. Those with the milder forms have little pigment development as time passes but are still highly susceptible to sunburn and skin cancer (Bashour, 2020; Brillant, 2015; Brocco, 2016; Gronskov et al., 2007; Jhetam & Mashige, 2019; Kerr et al., 2020; Kiluwa et al., 2022; Kromberg, 2018; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019; Suh, 2019).

In countries, particularly those closer to the equator, such as Africa and Brazil, with high prevalence of albinism, this poses a serious health problem (Bashour, 2020; Brillant, 2015;

Brocco, 2016; Gronskov et al., 2007; Kiluwa et al., 2022; Kromberg, 2018; Marcon et al., 2019; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). Skin cancer is the leading cause of morbidity and mortality among PWA who develop pre and malignant lesions at younger ages due to inadequate protection (Bashour, 2020; Brocco, 2016; Jhetam & Mashige, 2019; Kerr et al., 2020; Kiluwa et al., 2022; Kromberg, 2018; Marcon et al., 2019; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019; Suh, 2019).

In Tanzania, PWA is reluctant to seek and receive medical treatment; therefore, few PWA survive beyond 30 (Brillant, 2015; Kromberg, 2018; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019; Wright et al., 2015). The incidence of skin cancer in PWA of African descent is 1000 times greater than for the general population, with the head and neck being the most affected areas (Marçon & Maia, 2019; Reimer-Kirkham et al., 2019; Wright et al., 2015). For CWA, many schools do not have proper shelter to participate in outdoor activities; therefore, CWA is often excluded from such activities (Vernon et al., 2021). There are no cognitive or academic disabilities associated with albinism; therefore, CWA can perform with their non-disabled peers when their low vision is adequately addressed (Miyauchi & Paul, 2020; Opie et al., 2017; Siambombe & Isaac, 2018; Tambala-Kaliati, 2020). Exclusion from recreational activities affects CWA’s ability to stimulate cognitive, perceptual-motor development, and social and emotional well-being (Bento & Dias, 2017; Monti et al., 2017; Nijhof et al., 2018; Vernon et al., 2021; Yildirim & Akamca, 2017).

Psychological Barriers

Given the visual challenges inherent with albinism, there is great debate as to whether albinism is a disability or not. Naturally, an individual has a fundamental need to satisfy human development needs. When there is a disability or impairment that must also be managed, it can be difficult for the individual to conform to societal norms (Marini, 2020; Munyi, 2012; Parey, 2019). Society's reaction to albinism originates from many psychological barriers PWA face. These reactions lead to academic challenges that are not adequately addressed, leaving CWAs disadvantaged in education (Affram et al., 2019; Evance & Penda, 2018; Naiman & Azaliwa, 2021; Vernon et al., 2021). A review of current literature shows that myths and stigmatization are among the most noted barriers (Affram et al., 2019; Evance & Penda, 2018; Naiman & Azaliwa, 2021; Reimer-Kirkham et al., 2019; Vernon et al., 2021).

Myths Surrounding Albinism

For centuries, myths surrounding albinism have varied from country to country, ranging from fear to reverence. In the 17th century, PWA was believed to possess superhuman strength, seen as monsters, and thought unlucky in some parts; however, in others, PWA was viewed as doctors, specialists, and protected by God (Kromberg, 2018). As time and societies changed, so did the myths. Modern-day myths associated with albinism have a profound influence on the lives of PWA, starting from birth and continuing till their death. The myths affect family dynamics and interfere with access to education and social well-being (de Groot et al., 2020; de Groot et al., 2022; Kajiru & Mubangizi, 2019). In Western societies, where pale-skinned populations dominate, PWA often passes unnoticed. In regions dominated by darker-skinned people, the ability to go unnoticed is not an option. The myths surrounding albinism stem from a lack of knowledge despite the amount of research and documentation of albinism's genetic causation (Bradbury-Jones et al., 2018; de Groot et al., 2020; de Groot et al., 2022; Kajiru & Mubangizi, 2019; Lund, 2001; Reimer-Kirkham et al., 2019; Tambala-Kaliati, 2020; Wang & Ashburn-Nardo, 2019; Vernon et al., 2021; Zamani Varkaneh et al., 2022). Throughout the world, many myths surrounding albinism stem from the need for human beings to make sense of unexpected and unanticipated events (Bradbury-Jones et al., 2018; De Groot et al., 2020; de Groot et al., 2022; Kajiru & Mubangizi, 2019; Lund, 2001; Reimer-Kirkham et al., 2019; Tambala-Kaliati, 2020; Wang & Ashburn-Nardo, 2019; Vernon et al., 2021; Zamani Varkaneh et al., 2022). Reluctance to accept a genetic cause for albinism leads to beliefs that PWA is contagious, magical, a curse for past sins, and does not die (Aborisade, 2022; Affram et al., 2019; Baker et al., 2010; Bradbury-Jones et al., 2018; Chetty & Hargovan, 2020; Dapi et al., 2018; Kajiru & Mubangizi, 2019; Kerr et al., 2020; Kiluwa et al., 2022; Kromberg, 2018; Maunganidze et al., 2022; Mtonga et al., 2021; Reimer-Kirkham et al., 2019; Ringson, 2018; Tambala-Kaliati, 2020).

Contagious

One of the most common misconceptions about albinism is that the genetic condition is contagious. In the past, PWA was segregated in different countries, like the treatment of anyone with a physical disability. Today, segregation continues in public spaces such as schools where CWA is prevented from mixing with other children (Bradbury-Jones, 2018). The fear goes as far as people crossing the street to avoid walking next to someone with albinism, refusing to shake hands, or sitting next to someone with albinism.

The misconceptions of albinism also spread to health care. Healthcare professionals in southern Africa avoid PWA. If a child with albinism needs care at the hospital, a school nurse from a special school for the visually impaired must accompany the student to the hospital and administer treatment and care (Bradbury-Jones, 2018). If someone with albinism touches food or utensils, no one will use the utensils afterward, and the items are discarded (Bradbury-Jones, 2018).

The belief that albinism is contagious leads to different actions to avoid catching albinism. The most common response is spitting when seeing a PWA (Bradbury-Jones, 2018). In Zimbabwe, pregnant women spit on their stomachs when meeting someone with albinism to prevent their child from being born with albinism (Bradbury-Jones, 2018). In South Africa, individuals spit inside their shirts or hold their hair and turn away to ward off contagions (Bradbury-Jones, 2018).

Magical

In many parts of Africa, PWA is maimed, mutilated, and killed based on the belief that their body parts can bring good luck, success, and cure diseases (Aborisade, 2022; Affram et al., 2019; Baker et al., 2010; Bradbury-Jones et al., 2018; Chetty & Hargovan, 2020; Dapi et al., 2018; Kajiru & Mubangizi, 2019; Kerr et al., 2020; Kiluwa et al., 2022; Kromberg, 2018; Maunganidze et al., 2022; Mtonga et al., 2021; Reimer-Kirkham et al., 2019; Ringson, 2018; Tambala-Kaliati, 2020). Many are targeted for witchcraft-related rituals where their body parts are made into charms, such as miners when digging for gold, fishermen to increase their catch, and politicians to bring luck during elections (Bradbury-Jones, 2018; Chetty &Hargovan, 2021; Dapi et al., 2018; Kerr et al., 2020; Kiluwa et al., 2022). Children are the main target of many of these heinous crimes because human tissue is believed to make the most potent medicine, and children are easier to abduct (Bradbury-Jones, 2018; Chetty &Hargovan, 2021; Dapi et al., 2018; Kerr et al., 2020; Kiluwa et al., 2022). There is also the belief that hair, genitals, and bone amulets of PWA bring success; therefore, amulets are concealed in boats, businesses, homes, or clothing or scattered in the sea (Bradbury-Jones et al., 2018; Chetty & Hargovan, 2021; Dapi et al., 2018; Kerr et al., 2020; Kiluwa et al., 2022; Maunganidze et al., 2022). From a modern medical viewpoint, it is difficult to understand the superstitions associated with albinism and the unspeakable acts that fall upon children at the hands of uneducated individuals.

Curse

Spiritual meanings of albinism and its cause vary regionally and are directly linked to the treatment and security of PWA (Bradbury-Jones et al., 2018; Chetty &Hargovan, 2021; Dapi et al., 2018; Kerr et al., 2020; Kiluwa et al., 2022; Maunganidze et al., 2022; Reimer-Kirkham et al., 2019). Many regions commonly label PWA as ghosts (Bradbury-Jones, 2018). In Africa, any illness seen to be of supernatural origin, and many mothers are ashamed of their children; therefore, keeping them hidden from community members (Bradbury-Jones et al., 2018; Chetty &Hargovan, 2021; Dapi et al., 2018; Kerr et al., 2020; Kiluwa et al., 2022; Maunganidze et al., 2022; Reimer-Kirkham et al., 2019). In Tanzania, albinism is believed to be the result of a curse because a pregnant woman has looked at a person with albinism or was unfaithful therefore cursed with CWA (Bradbury-Jones et al., 2018; Chetty &Hargovan, 2021; Dapi et al., 2018; Kerr et al., 2020; Kiluwa et al., 2022; Maunganidze et al., 2022). Albinism in Zimbabwe is thought to be a curse resulting from a woman lying with an evil spirit or the parents being punished by God for past evil deeds (Bradbury-Jones et al., 2018; Chetty &Hargovan, 2021; Dapi et al., 2018; Kerr et al., 2020; Kiluwa et al., 2022; Maunganidze et al., 2022). Miyauchi & Paul (2020) found that people in Puerto Rico are more educated about albinism; however, the prevalence of myths and misconceptions is still highly responsible for the degrading treatment PWA face.

Death

Another common myth surrounding PWA is the death myth. Many believe PWA cannot die but disappear. This misunderstanding leads to the perception that PWA is dangerous, and when someone with albinism dies, strangers attend funerals to see if the person is dead (Dapi et al., 2018; Reimer-Kirkham et al., 2019). The death myth is used particularly by those who seek out to harm PWA and to justify their actions (Bradbury-Jones et al., 2018).

Everyone in the public does not hold the prevalence of certain myths and attitudes that permeate society. CWA is constantly battling to come to terms with a body that does not meet society's expectations of appearance, making it challenging to nurture social relationships while repeatedly being rejected (Gaigher et al., 2002; Likumbo et al., 2021). The myths and misconceptions associated with albinism can cause those affected great anguish and despair, manifesting into psychological problems (Affram et al., 2019; Evance & Penda, 2018; Naiman & Azaliwa, 2021; Reimer-Kirkham et al., 2019; Vernon et al., 2021). Albinism is considered a disability, and sufferers are often marginalized (Ojedokun, 2018). Throughout history, individuals with disabilities have been scrutinized, discriminated against, and stereotyped out of a lack of knowledge and fear (Ojedokun, 2018; Reimer-Kirkham et al., 2019).

The Role of Stigmas

Stigmas are one of the more damaging psychological barriers to education (Affram et al., 2019; Dapi et al., 2018; Evance & Penda, 2018; Naiman & Azaliwa, 2021; Vernon et al., 2021). Stigmas affect self-respect, esteem, and acceptance (Affram et al., 2019; de Groot et al., 2020; de Groot et al., 2022; Germain et al., 2021; Kleinman & Hall-Clifford, 2009). For PWA, stigmas are destructive and affect the quality of inclusive education for children with albinism during the formative years of a child's academic career (Dapi et al., 2018; de Groot et al., 2022; Kasamba, 2021). Stigmas surrounding albinism are that those with albinism are contagious and not human, therefore undeserving of human rights (Affram et al., 2019; de Groot et al., 2022; Likumbo et al., 2021). These stigmas have led to the discrimination and isolation of CWA. Isolation can be individual isolation or isolated due to peers and teachers ostracizing the individual by separating them from cognitive and motor development activities based on assumptions (Affram et al., 2019; Evance & Penda, 2018; Germain et al., 2021; Naiman & Azaliwa, 2021; Vernon et al., 2021). Stigmatization of PWA affects all aspects of a person’s life; social, family dynamics, and educational attainment. (Affram et al., 2019; Evance & Penda, 2018; Vernon et al., 2021).

Social Stigmatization

Norms are defined as rules for behavior that dictate a group’s actions and expectations (Neville et al., 2021). Norms exist for individuals, families, and society and emerge during interactions when exposed to the opinions or actions of others. After a while, these norms become a point of reference when making judgments and later are adopted as personal norms to make sense of new events (Neville et al., 2021). Over time, these norms begin to form, shape, and change social identity. Norms are tied to social identity and relationships (Chetty & Hargovan, 2021). Social identity helps individuals belong to groups and describes what is involved in being a group member and group norms (Chetty & Hargovan, 2021). Individuals adopt group norms and begin to behave accordingly. However, things are deemed abnormal when there is a deviation from the norms (McDonald & Crandall, 2015; Neville et al., 2021). PWA white skin color and visual impairments deviate from societal norms and cause displayed or hidden stigmatizing behaviors during social interactions (Brocco, 2016; Chetty & Hargovan, 2021). Social stigmatization can be coped with or nurtured by forming social identities from interactions with family, neighbors, community, media, and support groups (Brilliant, 2015; Brocco, 2016).

Typically, children attend school, build friendships, and learn socialization. As a result of stigmatization, CWA often tries to manage their condition in ways that guard against being stigmatized (Wang & Ashburn-Nardo, 2019). In countries where myths supersede scientific knowledge, many CWA are segregated from their peers and teachers out of fear of the unknown and the perception that albinism is contagious (Bradbury et al., 2018; Reimer-Kirkham et al., 2019). CWA often distance themselves from social settings, making themselves invisible and lacking social skills. There is also a constant battle within themselves regarding their body image and why society often rejects it. As children age, their ability to make friends becomes even more complicated, causing them to withdraw (Aborisade, 2022; Maia et al., 2015; Miyauchi & Paul, 2020).

When CWA is marginalized socially, it affects the ability to learn how to build and maintain healthy social relationships, which are essential for social well-being (Reimer-Kirkham et al., 2019). From a developmental perspective, social interactions that occur during school activities such as recess offers children the opportunity to improve their social skills and address the positive and negative consequences of their behavior (Bento & Dias, 2017; Kerr et al., 2020; Monti et al., 2017; Nijhof et al., 2018; Vernon et al., 2021; Yıldırım & Akamca, 2017). The environment in which a child resides significantly shapes experiences, opportunities, and the future (Darling-Hammond & Cook-Harvey, 2018; Obaki, 2017; Strife & Downey, 2009; Wilson, 2018). When this environment is hostile and surrounded by ridicule and isolation, a child will lack the appropriate social skills that are needed later in life to sustain healthy relationships and function as a well-rounded adult (Darling-Hammond & Cook-Harvey, 2018; Obaki, 2017; Strife & Downey, 2009; Wilson, 2018). Statistically, PWA often employs avoidance or self-isolation to avoid being bullied or rejected by their peers (Franklin et al., 2018; Hong et al., 2006; Kerr et al., 2020; Ojedokun, 2018). PWA are also more emotionally unstable and have less assertive personalities; therefore, they are more prone to social avoidance tendencies (Franklin et al., 2018; Hong et al., 2006). Without adequate social skills, one cannot develop organizing ability, problem-solve, recognize oneself, or enhance social competence (Khusnidakhon, 2021; Monti et al., 2017; Nijhof et al., 2018; Vernon et al., 2021; Yıldırım & Akamca, 2017). The public lacks knowledge of albinism as well as PWA; this social discrimination becomes a barrier to relationships, which affects the ability to possess the social skills to interact with others, find jobs, and lead a whole social life (Khusnidakhon, 2021; Monti et al., 2017; Nijhof et al., 2018). The inability to conduct a full social life leaves PWA in a state of economic vulnerability due to educational and employment lack, leading to lower financial status (Brocco, 2016; Marçon & Maia, 2019; Reimer-Kirkham et al., 2019).

Family

Albinism is a condition that affects the individual and their family medically, socially, and psychologically; the social and psychological effects are more damaging than the medical issues (Marçon & Maia, 2019). Individuals with albinism are shunned socially because their outward appearance does not conform to societal norms (Marçon & Maia, 2019). When this happens, PWA avoid social situations going unnoticed, making them more emotionally unstable and less assertive. Society, friends reject PWA, and often, family (Brilliant, 2015). When an individual is born into a family whose appearance is strikingly different from their other family members, concerns and beliefs run rampant regarding its cause. Many people believe the cause of albinism is the child conceived during menstruation, curse, or punishment by the gods for an ancestor’s past discretions (Brilliant, 2015; Brocco, 2016; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). No matter how extreme and medically impossible, these beliefs assert within family dynamics and can cause rifts in families. (Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). Mothers face stigmas, distress, and accusations of infidelity from within the family when a child is born into a family of African or mixed descent (Marçon & Maia, 2019). For PWA to be accepted within a community, acceptance is centered on the surrounding community and the perceptions towards PWA. Combining this way of life and the stigmas associated with albinism, many CWA are raised by single mothers in poverty and exclusion (Kerr et al., 2020). Fathers often do not accept their CWA and will abandon the family; other family members want or plot to kill newborns when CWA is born (Kerr et al., 2020). In some countries, newborns are killed due to albinism being viewed as a curse damaging the entire family's reputation (Brillant, 2015; Brocco, 2016; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019).

In countries characterized by solid male dominance and patrilineal inheritance, although the mothers are fond of their children with albinism, the decision to reject them lies with the father (Brocco, 2016). Therefore, if left, the mother returns to the family while she and the child are excluded by the father (Brocco, 2016; Reimer-Kirkham et al., 2019). The patriarch plays a significant role in family dynamics in Tanzania. PWA is readily accepted if there is already someone with the condition or if the grandfather affirms in front of all relatives that the child belongs to the family (Brocco, 2016). Within family networks in many countries where PWA is stigmatized and socially discriminated against lies a strong connection between social hierarchies and unequal distribution of power because albinism is a condition that enhances vulnerabilities and affects the social status of a person (Brocco, 2016; Reimer-Kirkham et al., 2019).

Aside from paternal rejection, some CWA can also face maternal rejection, which affects psychological well-being (Kerr et al., 2020). Once a child is born with albinism, discrimination begins and is reflected in the mother (de Groot et al., 2022; Franklin et al., 2018; Kajiru & Mubangizi, 2019). Due to constant speculations and ridicule, mothers do abandon their children to be with their spouse or other unaffected children (Anshelevich et al., 2021; de Groot et al., 2022; Franklin et al., 2018; Kajiru & Mubangizi, 2019; Kerr et al., 2020; Mazibuko & Kromberg, 2018; Ojedokun, 2018; Phatoli et al., 2015). Many CWA are left with other family members, such as grandparents, while some are abandoned and left to care for in an orphanage or worse (Groot et al., 2022; Franklin et al., 2018; Kajiru & Mubangizi, 2019; Kerr et al., 2020). The marginalization of CWA does not stop at home; there are also occurrences in the educational setting.

General Education

The concept of school in the United States came about during the 19th century and was based on the belief that schooling makes good citizens (Zigmound & Kloo, 2017). In the 1830s, Horace Mann advocated for creating public schools that would be available to all children free of charge (Zigmound & Kloo, 2017). Schools would promote class cohesion and prepare students for good jobs (Kober, 2020; Zigmound & Kloo, 2017). Initially, schools were more commonly found in Northeast cities than in rural or other areas of the US (Kober, 2020; Zigmound & Kloo, 2017). Over time, public schools began to appear more in other parts of the US. Initially, schools focused on teaching reading, writing, and arithmetic in a general setting, now known as general education (Kober, 2020; Zigmound & Kloo, 2017).

General education is the primary free public education available to all (Zigmound & Kloo, 2017). General education is dictated by state and local school districts that set rules and regulations for compliance with the curriculum (Zigmound & Kloo, 2017). General education is group-oriented; however, due to educational reforms, it has begun to embrace differentiated instruction to reach diverse learners (Zigmound & Kloo, 2017). General education is universal and guided by academic tests based on state standards for the curriculum (Smith & Tarantino, 2019; Zigmound & Kloo, 2017). Students are placed in classes that vary in size (Smith &

Tarantino, 2019; Zigmound & Kloo, 2017). Class size affects how much content is covered and how much time the teacher can give to individual students. Students differ in academic ability, language proficiency, and interest (Zigmound & Kloo, 2017). Overall, general education is, as the name implies, a public, broad place taught by content-specific teachers (Smith & Tarantino, 2019; Zigmound & Kloo, 2017).

Special Education

In contrast, special education is specialized instruction offered to specific individuals (Lipkin & Okamoto, 2015; Smith & Tarantino, 2019; Zigmound & Kloo, 2017). Unlike general education, special education is only offered to some with a qualifying disability, affecting their ability to access the general education curriculum (Lipkin & Okamoto, 2015; Smith & Tarantino, 2019; Zigmound & Kloo, 2017). Special education provides services specific to students' needs (Zigmound & Kloo, 2017).

Historically, students with disabilities were not educated in public schools (Zigmound & Kloo, 2017). Many were placed in institutions or hospitals or left home without educational provisions (Lipkin & Okamoto, 2015; Smith & Tarantino, 2019; Zigmound & Kloo, 2017). The latter portion of the 20th century brought about the Education of All Handicapped Children Act, which later became the Individuals with Disability Education Act (IDEA) that eventually called for more inclusive public education (Lipkin & Okamoto, 2015; Smith & Tarantino, 2019; Zigmound & Kloo, 2017). IDEA resulted in mandates for a free, appropriate public education (FAPE) for individuals with disabilities in the least restrictive environment (LRE), which gave rise to inclusive teaching (Lipkin & Okamoto, 2015; Smith & Tarantino, 2019; Zigmound & Kloo, 2017).

Inclusive teaching suggests that all students can thrive regardless of background or disability (Webster, 2014). Inclusive education has been part of the United States, Canada, England, and Swedish school systems since 1975, and some are further along than the US at moving toward fully inclusive classrooms (Lipkin & Okamoto, 2015; Zigmound & Kloo, 2017). Some countries, such as Georgia, Malaysia, and Romania, are not as inclusive to those with disabilities (Lipkin & Okamoto, 2015; Zigmound & Kloo, 2017).

With the newly mandated inclusion of students with disabilities came the decision to consider albinism a disability. Studies show that educational barriers for individuals with OCA can impact academic performance (de Groot et al., 2020; de Groot et al., 2022; Kasamba, 2021; Mtonga et al., 2021). Many challenges CWA experience can be helped with special education services; however, the problem lies in adequately supporting the student.

Administrators

Many school systems are unsure where to classify CWA, given that CWA have a visual impairment but are not blind. Some parts of Africa are deciding to place CWA in special schools for the deaf and blind, while others put them in all special education classes or split time between general education and special education classes (Mtonga et al., 2021; Zamani Varkaneh et al., 2022). Regardless of the placement, many school systems are trying to help with the physical obstacles students face (Anshelevich et al., 2021; Kasamba, 2021; Mtonga et al., 2021; Zamani Varkaneh et al., 2022). Some school systems are not always appropriate, and the effectiveness, regular or special, is dependent upon the environment and the culture in which CWA is viewed (Mtonga et al., 2021; Corn & Lusk, 2018a; Corn & Lusk, 2018; Kabwe & Mandyata, 2020; Yasar, 2022). Caucasians with albinism in Europe, the United States, and Australia are not as distinguishable as those of African, Asian, and South American descent with albinism; therefore, Caucasians with albinism are readily accepted by society (Chetty & Hargovan, 2021). Columbians with albinism do not see the condition as a disability and are unaware of the available services. Brazilians must prove their disability to access services (Chetty & Hargovan, 2021). Nevertheless, inclusive teaching outpaced the availability of qualified teachers; therefore, the need for teachers rose to support diverse classrooms.

Teachers

Historically, teacher preparation education did not prepare general education teachers to support a diverse classroom (Kober, 2020; Zigmound & Kloo, 2017). General education teachers are prepared to teach specific subject matter and academic standards (Kober, 2020; Zigmound & Kloo, 2017). Special education teachers are prepared to teach individuals with various learning and emotional needs (Zigmound & Kloo, 2017). Therefore, many teachers, new and veteran, need to prepare to address individual differences (Kober, 2020; Zigmound & Kloo, 2017). In attempts to address shortcomings, many teacher preparation programs include brief coursework in urban education, English language learners, and students with disabilities (Kober, 2017). Nevertheless, research has shown that general education teachers favor group-focused rather than individual-student-focused strategies (Kober, 2020; Zigmound & Kloo, 2017). Despite classroom changes, the teacher education curriculum has remained the same to reflect the unique classroom dynamics. One such challenge is the uniqueness of PWA and the needs in the general education classroom. The lack of programs that are available to pre-service or veteran teachers, school administrators, or stakeholders that can improve knowledge and awareness of special needs students and albinism in the educational setting aids in prolonging the barriers to education PWA face (de Groot, 2020; de Groot et al., 2022).

Elementary Student Interactions

Children face daily stressors during their daily routine (Brocco, 2016; de Groot et al., 2022; Herbell et al., 2020; Reimer-Kirkham et al., 2019). The ability to deal with these daily stressors is linked to their social well-being (Brocco, 2016; de Groot et al., 2022; Herbell et al., 2020; Reimer-Kirkham et al., 2019). As aforementioned, many educational barriers originated in the school setting due to implementing inclusive education with IDEA (Lipkin & Okamoto, 2015; Vernon et al., 2021). However, elementary school students must fully develop the appropriate skills to manage their behaviors and emotions (Reimer-Kirkham et al., 2019).

Special Education Student Interactions

Special education is available to ensure access to the general education classroom (Kauffman et al., 2017). Accommodations and modifications are made to provide access, such as preferential seating, one-on-one instruction, extended time, movement close to the board when needed, and assistive technology (Anshelevich et al., 2021; Zamani Varkaneh et al., 2022). If required, students can be referred for special education services to get additional support with barriers from supplemental resources such as an occupational therapist, speech therapist, or a teacher of students with visual impairments (TVI) (Kauffman et al., 2017).

CWA qualify for special education services due to their visual impairment and are given vision services to combat many of the visual challenges of albinism. With the support of a visually impaired teacher, CWA can get help in the classroom with assistive technology, including using a slant board, low vision paper, magnifier, or iPad, to name a few services available (Siambombe & Isaac, 2018). Although schools are pushing for the inclusion of students with disabilities, many CWA are taught in classrooms with non-disabled peers and are subjected to unfair treatment due to a lack of knowledge on how to adequately support them (Kauffman et al., 2017; Siambomb3 & Issac, 2018).

Students with Albinism Interactions

The variation of pigmentation in individuals with OCA compared to their counterparts gives rise to segregations of CWA within the educational setting (Bradbury-Jones et al., 2018; Corn & Lusk, 2018; Jhetam & Mashige, 2019; Kerr et al., 2020). CWA are often not allowed to attend school out of fear or shame felt by their family members (Jhetam & Mashige, 2019; Kerr et al., 2020). Many are hidden at home, away from public scrutiny. Within the educational setting, PWA face threats to their safety, discrimination, and abuse that brings about psychological and emotional deficits (Bradbury-Jones et al., 2018; Corn & Lusk, 2018; Jhetam & Mashige, 2019; Kerr et al., 2020; Kiluwa et al., 2022). Events such as incessant bullying and name-calling based on their physical appearance cause PWA to be more vulnerable to stressors in adulthood and difficulty coping and adjusting (Brocco, 2016; Kerr et al., 2020; Kiluwa et al., 2022; Strom et al., 2018). In the Congo, PWA is called mbunzu gozo (black eater of manioc); in Mali, gomble (red man) due to their susceptibility to sunburn; in Malawi, mzungu (white man) and napwere (pea-brown color). In Brazil, PWA is called peeled cockroaches and white rats; in Malaysia, PWA is called ghosts, white people, or even aliens. In India, PWA is called a snowman or yeti (Chetty & Hargovan, 2021; Reimer-Kirkham et al., 2019). These threats are significant sources of trauma that cause extreme distress during the encounter and have lasting effects for months and years to follow (Kiluwa et al., 2022; Reimer-Kirkham et al., 2019).

Traumatic events in the educational setting manifest themselves in low academic performance in grades, class participation, and social interactions (Kiluwa et al., 2022; Reimer-Kirkham et al., 2019; Vernon et al., 2021). As a result, grades decline due to reluctance to ask for help. Social interactions decrease due to fear of rejection, giving rise to feelings of shame, hopelessness, depression, or dropping out of school, impacting the quality of life in adulthood

(Brocco, 2016; Franklin et al., 2018; Kiluwa et al., 2022; Marcon & Maia, 2019; Mubangizi & Kajiru, 2020; Reimer-Kirkham et al., 2019). In countries such as Africa, where the economy is agriculturally based for many families affected by albinism, the inability to obtain proper education places PWA in lower socioeconomic status by only being able to find employment cultivating their field (Brocco, 2016; Marco & Maia, 2019; Reimer-Kirkham et al., 2019). Studies show that low socioeconomic status affects life improvement and restricts access to basic needs, access to healthcare, and education, as well as increased vulnerability to trauma (Franklin et al., 2018; Kiluwa et al., 2022; Mubangizi & Kajiru, 2020; Tambala-Kaliati et al., 2021).

Brocco (2016) noted that individual and moral concerns influenced by family, economic status, friends, and religious thoughts affect the social and psychological management of living with albinism. Vernon et al. (2021) supported Brocco (2016) by arguing that the psychological barriers individuals face, social stigma, and discrimination are among the most impactful, as these psychological barriers harm dignity and self-respect. Kiluwa et al. (2022) supported the studies of Brocco (2016) and Vernon et al. (2021), stating that “chronic exposure to discrimination and violence can predispose people with albinism to mental health challenges, affecting their psychological well-being” (p. 7).

For individuals with albinism, the ability to manage stressors is significantly reduced due to feelings of low self-worth and esteem. Studies have shown that children benefit immensely from having a wide range of coping strategies when confronted with life’s daily challenges (Melham, 2021). School administrators must be aware of the lack of coping skills development in their schools and provide ways to support students who need coping and assertiveness skills. Assertiveness training reduced the number of inappropriate behaviors in schools while increasing the knowledge of the appropriate coping skills (Sofianopoulou et al., 2021). Students with albinism with low social well-being have poor coping skills and thus turn to negative behaviors such as aggression or withdrawal (Reimer-Kirkham et al., 2019; Sofianopoulou et al., 2021). By focusing on coping skills and assertiveness training, students with albinism can improve their academic performance and social well-being because coping skills improve an individual's stressful situation (Melham, 2021). Perry et al. (2018) found that children are more at risk for poor academics, peer relationships, anxiety, depression, and irregular emotions when coping and assertiveness skills are lacking.

The damage from the psychological barriers presents lasting effects that can hinder educational attainment at all levels. Studies have shown that experiences of discrimination and stigmatization affect education, affecting socioeconomic status (Aborisade, 2021; Affram et al., 2019; Bradbury-Jones et al., 2018; Chetty & Hargovan, 2021; Corn & Lusk, 2018a; Dapi et al., 2018; Yasar, 2022). Low socioeconomic status affects the ability to improve life by limiting access to adequate shelter, food, education, and health care (Kiluwa et al., 2022). Children who learn appropriate resiliency skills have more assertiveness and self-esteem (Koohfini & Kheirabadi, 2020). For CWA to succeed academically, CWA must be prepared to handle and overcome the psychological barriers placed upon them (Zamani Varkaneh et al., 2022). Assertiveness training helps students improve their perception of their experiences and motivates them to deal with stressful situations such as bullying, isolation, name-calling, and discrimination more appropriately (Perry et al., 2018; Veijalainen et al., 2019; Zamani Varkaneh et al., 2022). Children who learn how to effectively navigate their mental health, strengthen their self-management skills, decrease their subjective distress, and improve their social skills with peers are more likely to excel academically (Perry et al., 2018; Veijalainen et al., 2019; Zamani Varkaneh et al., 2022).

Aside from coping skills and assertiveness training, there is a need for changes and practices that are developed to support the psychological needs of students with albinism. Social stigmas and discrimination have a damaging effect on the social well-being of an individual (Vernon et al., 2019). For students with albinism who are already ostracized for appearance, the psychological impact of stigmas must be addressed to serve students with albinism. By improving the support available to individuals with albinism, students are less likely to have negative behavior, such as withdrawal, when confronted with a stressor (Fenwick-Smith et al., 2018). de Groot et al. (2022) conducted a study to reduce albinism-related stigma via radio programs aimed at improving public education on albinism to dispel myths and stereotypes surrounding albinism. Their study effectively improved peoples' knowledge and attitudes toward people with albinism (de Groot et al., 2020; de Groot et al., 2022). Research has already shown that albinism can break up families; therefore, it is detrimental to explain to parents, more importantly, mothers what albinism is, how to deal with albinism, overcome the negative beliefs and views from family members and the community (Aborisade, 2021; Affram et al., 2019; Brillant, 2015; Brocco, 2016; Chetty & Hargovan, 2021; Kerr et al., 2020; Kromberg, 2018; Mazibuko & Kromberg, 2018; Tambala-Kaliati, 2020). Studies show that once community awareness improved and relationships were established, community members were no longer afraid to associate with PWA (Bradbury-Jones, 2018; Brocco, 2016; Chetty & Hargovan, 2021; Kromberg, 2018;). Therefore, this study explores the psychological barriers caregivers endure as a CWA access general education classroom.

Summary

For many years, the attitudes and treatment of PWA have varied, with superstition and infanticide being replaced with attempts at understanding and protection, only to cycle back to the past, creating barriers. The educational barriers associated with albinism have negatively impacted the success of children with albinism in the general education classroom in primary schools. Because of this, researchers have extensively researched the educational barriers in general education classrooms in the form of physical and psychological barriers to education. Studies show that common physical barriers are teachers' lack of accommodations, little access to necessary assistive technology, poor or inadequate classroom management and arrangement, insufficient accessibility of school grounds, and inferior classroom materials. Psychological barriers included bullying, isolation, discrimination, and stigmatization (Affram et al., 2019; Kasamba, 2021; Vernon et al., 2021; Zamani Varkaneh et al., 2022).

Despite advancements in medicine, PWA still face stigmatization, discrimination, and violence (Chetty & Hargovan, 2021). CWA face personal insecurities and barriers to education that expose them to endure long-term poverty. In Africa, where albinism is more common, CWA face more significant obstacles than in other countries, given that albinism is still surrounded by secrecy, myths, and a lack of understanding (Chetty & Hargovan, 2021). The impact of myths and stigmas on the lives of PWA and their families presents a need to address these challenges. Amongst the most recommended is education; to help people understand albinism and how to interact, as well as help PWA. By educating PWA, their families, and healthcare worker, there is the hope that it can help overcome the myths and misconceptions surrounding albinism and improve healthcare access (Bradbury-Jones, 2018).

Using Goffman's social stigmas of character, physical, and group identity to explain how these stigmas impact children with albinism helps show the connection between educational performance and educational barriers (Goffman, 2009). Current research only addresses the physical obstacles in the classroom and a few on including PWA in the general education setting.

This transcendental phenomenological study aims to understand the psychological barriers CWA parents face when accessing the general education classroom.

CHAPTER THREE: METHODS

Overview

The purpose of this transcendental phenomenological study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. Chapter Three introduces the transcendental phenomenological research design, procedures, and data analysis. The chapter also provides research questions, researcher positionality, researcher role, data collection methods, trustworthiness, and ethical considerations.

Research Design

Qualitative research provides insight into real-world problems, allows for understanding views and perceptions, helps develop concepts, and can inform the development of interventions or knowledge barriers to implementation (Denny & Weckesser, 2018). The qualitative research approach is appropriate to understand how stigmas create psychological barriers to education for individuals with albinism because qualitative research involves a naturalistic approach to the world (Creswell & Poth, 2018). Researchers can observe participants in natural settings while trying to interpret and bring meaning to familiar themes. Qualitative research is used when a problem needs to be explored (Creswell & Poth, 2018). For individuals with albinism, the problem is that since the passing of the Individuals with Disability Education Act of 1975, students with disabilities are required to access a free, appropriate public education in the least restrictive environment (Lipkin & Okamoto, 2015; Vernon et al., 2021). However, students with albinism face many challenges when accessing the free appropriate public education CWA is legally entitled to receive (Affram et al., 2019). Despite accommodations in the classroom to help students overcome physical barriers, PWA still needs to overcome the obstacles to education due to the need for adequate teacher training and programs available to assist unique learners.

For this study, a transcendental phenomenological study was utilized to emphasize the lived experiences of caregivers of CWA and identify the psychological barriers of CWA in the educational setting. Transcendental phenomenology seeks to add dimensions to the studies of human experiences. Noema is defined as “not the real object” but the phenomenon, that which is “perceived and experienced” (Moustakas, 1994, p. 29). Noesis is the act of perceiving, feeling, and thinking about how the phenomenon was experienced (Moustakas, 1994). Noesis and noema create a deeper understanding and connection between an individual and the world (Moustakas, 1994). Preconceived ideas or epoché are set aside to present the phenomenon through unbiased lenses, allowing for a true meaning of the phenomena to be explained (Moustakas, 1994). Through the transcendental phenomenology tenets noema, noesis, noeses, noetic, and epoché, a deeper understanding of the lived experiences can be ascertained (Moustakas, 1994). Data was analyzed for themes using the Moustakas transcendental phenomenology research framework to generate an explicit structure of meaning to the lived experiences (Moustakas, 1994). Given the unusual nature of the topic, a transcendental phenomenological study will help focus on the essence of the lived experiences of parents of children with albinism. Furthermore, this research design is appropriate because it allows for a better understanding of the lived experiences of PWA when dealing with barriers to education and how to help them.

Research Questions

Qualitative research questions were used to help guide the development of the study. This study is guided by one central research question and three sub-questions to guide the investigation of the phenomenon. The central research question explores the phenomenon, while the sub-questions break down and clarify the main question and provide more specific details. The following research questions guide this transcendental phenomenological study.

Central Research Question

What are the lived experiences of parents of children with albinism in school?

Sub-Question One

What affect does albinism have on a person's character/mentality in school?

Sub-Question Two

What affect does albinism have on a person on a student physically in school?

Sub-Question Three

What affect does albinism have on a person's ability to identify with a particular group/race/religion?

Setting and Participants

Setting

The setting for the study took place in general education classrooms. The rationale for looking at general education classrooms is due to IDEA's least restrictive environment policy, in which students with disabilities are placed in a learning environment with their non-disabled peers as much as possible (Parey, 2019). A general education classroom typically consists of thirty to thirty-two students and a certified teacher (Kiramba et al., 2022). However, general education classrooms are now extremely diverse given IDEA's push for the least restrictive environment and inclusion of children with disabilities. An inclusive general education classroom is made up of a mixture of students with and without disabilities (Parey, 2019). In general education classrooms with a high number of students with disabilities, a second teacher certified in special education will also be available in the classroom to assist the specific needs of students with disabilities (Parey, 2019). The leadership structure of the classroom in a two-teacher or co-taught classroom is shared between the general education teacher and the special education teacher regarding discipline, classroom expectations, and grades (Kiramba et al., 2022; Parey, 2019). The special education teacher is responsible for implementing the student's individual education plan (IEP) and the general education teacher is also responsible for familiarizing themselves with the disabilities of the students to differentiate the content to best suit the student's individual needs (Kiramba et al., 2022).

Participants

Participants in this study were eleven parents of individuals with oculocutaneous albinism. Participants range in age from 18 of age and older. Five participants were of African/African-American descent. Six participants were Caucasian. The gender of participants were all females. Participants in the study were all parents or caregivers of PWA and provided information on the child's experiences as a parent of PWA trying to help the child succeed in the classroom. Participants were all members of a group on a public platform available to anyone. However, the group's name was not provided, and the pseudonym, All About Albinism, was used. The group is for those with a loved one with albinism. Before joining the group to obtain access to the group members, the researcher had to answer specific criteria questions beforehand to get approval from the social media group administrators.

Recruitment Plan

Recruitment occurred using the social media group All About Albinism. The group has a membership of approximately 1,000 individuals. The individuals in the sample are parents or caregivers of those with albinism. The type of sampling to recruit participants was purposeful sampling using social media. A post-seeking participant with the study information was placed on the support group page to locate participants. The sample size of eleven participants consisted of caregivers of children with OCA who were recruited until saturation was reached. Saturation is reached when coding; there are no new codes, and additional data does not lead to new emergent themes (Saunders et al., 2018). Once the participant pool was generated, informed consent was obtained to ensure participants knew the right to withdraw at any time.

Researcher's Positionality

Primary school is an important time in a person's life that builds the foundation for self-identity and defines their attitude toward others (Affram et al., 2019). Therefore, it is crucial to understand how society and social interactions can create psychological barriers PWA endure in general education classrooms. This section will provide a description of the motivation for conducting this study, followed by my philosophical assumptions that will guide this study.

Interpretive Framework

The interpretative framework I used for this study is social constructivism. Through a social constructivist lens, I sought to understand better the lived experiences of caregivers of CWA psychological barriers that individuals with albinism face and how to overcome them. Social constructivism is based on developing meanings through participants' interactions with the researcher's background and how the information is interpreted (Creswell & Poth, 2018). This topic is very personal because I have three children with albinism, and I desire to know how to help them best and individuals like them. Therefore, a social constructivist lens is the most appropriate for the choice of topic.

Philosophical Assumptions

Levers (2013) defines philosophical paradigms as sets of beliefs and practices that control inquiry within a discipline by providing lenses, frames, and processes through which study is carried out. Paradigms are used to explain the philosophical framework a research study is based on (Levers, 2013). Philosophical paradigms are important because they help build the research's foundation (Levers, 2013). For this study, articulating the ontological, epistemological, and axiological assumptions helped me understand the lens through which I view the world and how I approached my research.

Ontological Assumption

Ontological assumptions are focused on the belief in realities (Creswell & Poth, 2018). When conducting a qualitative study, a researcher must accept multiple facts (Creswell & Poth, 2018). Multiple facts are evident during a phenomenological study when a researcher collects data through interviews, surveys, and data from previous research studies. The data is used to express the participant's experiences and views. As a researcher conducting qualitative research on the psychological barriers experienced by students with albinism, the nature of realities will be present in the detailed accounts captured from the participants during interviews. My ontological views are constructive in that reality is subjective and based on experiences in the world. I believe that the perceptions and actions of others create a continuous social phenomenon. The actions of others explain the meanings of this phenomenon. The actions of society explain the perceptions of PWA, and the barriers placed upon them.

Epistemological Assumption

Epistemological assumptions limit the distance between the researcher and participants (Creswell & Poth, 2018). When conducting a qualitative study, the researcher may complete fieldwork to show epistemological assumptions. Given my social constructivist view on reality, I believe knowledge and what is known to be based on social relationships and interactions. I also believe that social interactions shape a person's truth. My study displayed my epistemological position through observations and interviews. I collected firsthand information through these primary sources to understand what the participant wants to say (Creswell & Poth, 2018). By exploring the lived experiences of caregivers of CWA, I believe their truth is shaped by their experiences with CWA and how psychological barriers affect education and home life.

Axiological Assumption

Axiological assumptions focus on values' role (Creswell & Poth, 2018). When conducting a qualitative study, the researcher displayed their axiological beliefs by acknowledging their role and identifying their biases in the foreground. Great value is placed on participants and the information being shared because of my closer nature to the topic. The audience is also important because society helps shape my participants' experiences and truths. My topic is personal, given that I have three children with albinism and one currently in elementary school. My son is in elementary school, and trying to learn how to help him overcome any barriers is the reason why I chose my topic. I displayed my axiological assumptions by acknowledging my role and biases during the study.

Researcher's Role

My role in this study was as a researcher with a personal connection to the topic of the study. I am a parent with three children with albinism, one of whom is currently in elementary school and the driving force for the subject of this study. I have experience dealing with the aftermath of individuals' thoughtless and cruel remarks toward those with albinism as a parent. I do not have any relationship or authority over any of the participants. My role in the research setting is as a member. I am a member of the public social media groups from which the participants will be sampled. I joined these social media groups to learn more about albinism, network with other parents and individuals with albinism, and find potential participants for my study. The biases I bring are parental in that I am defensive regarding my children's psychological well-being. I am in the same position as the participants; therefore, my personal feelings and experiences are among my biases. I empathize with the participants and their children, which can constitute biases. This position can sometimes make me less suspicious of my children when I am told someone was mean or said something unkind to them, given the past experiences my children and I have had with others regarding how CWA is perceived by society. For a transcendental phenomenological study, the lived experiences of caregivers of CWA provide first-hand knowledge of the barriers CWA face. To successfully gather an unbiased description of the data during data analysis, I bracketed and was extremely mindful not to let my biases skew the interpretation.

Procedures

This transcendental phenomenological study was conducted in seven steps. First, I acquired conditional approval from the institutional review board (IRB) at Liberty University to conduct the study (see Appendix A). Given the generic environment, the study did not occur in a physical setting; therefore, site permissions did not need to be obtained. Next, I began collecting data once full IRB approval was received. Third, the recruitment for participants utilized social media, given the uniqueness of the participants. Participants were required to comprehend and sign an informed consent before participating in the research study (see Appendix B) that outlines the purpose of the study and the participant's role in the research study. The fourth step, data was collected using primary sources to build the research and support the findings. Virtual interviews with participants were conducted via Microsoft Teams. Video Interviews were recorded and transcribed using Microsoft Teams. The fifth step was conducting focus group sessions with four to five randomly selected participants to help show any commonly shared themes amongst the participants. Similar to the individual interviews, focus groups were conducted virtually via Microsoft Teams. The recordings and transcriptions were also conducted via Microsoft Teams. The final step was to collect data using individual journal prompts to provide other firsthand experiences of participants' accounting of events. The journal prompts used focused on the participants' psychological barriers. The collected data was analyzed and coded for the identification of patterns and themes using thematic analysis according to Moustakas' method of analysis (Moustakas, 1994). Information discovered during the collection process was synthesized into themes that capture the essence of the lived experiences of caregivers of CWA.

Data Collection Plan

Data was collected using primary sources, including individual interviews, focus groups, and journal prompts. Using primary sources provided an understanding of the psychological barriers to education that caregivers of CWA experience while attending general education classes during their primary school years. Data was collected in the following order: interviews, focus groups, and journal prompts. Interviews were collected to ascertain participants' voices and lived experiences with children with albinism in the general education classroom. Focus groups were used to gather more detailed information on the experiences and beliefs not obtained through interviews. Journal prompts were collected to provide a last opportunity to let the researcher know anything not provided in the previous collection methods. Data triangulation was achieved by collecting data from multiple sources (Norwell et al., 2017).

Individual Interviews

To help understand the barriers and acquire insight into the lived experiences of parents of a PWA is to interview individuals ages 18 and older and obtain their voiced live experiences on how it was caring for, supporting, and raising a child with albinism. I structured the interview questions by initially establishing a rapport with the participants. The interview questions progressed to identify phenomena using the participants' voices. The interview occurred using Microsoft Teams. Analysis of the data collected followed Moustakas's method of analysis. Interviews were conducted virtually with the participants using Microsoft Teams. The interviews were recorded using Microsoft Teams and transcribed into usable formats using Microsoft Teams. I read the transcripts and memoed to ensure I understood the participant's words thoroughly and set aside my prejudices and biases. Interview transcriptions were analyzed for significant statements or quotes that explain parents' lived experiences or horizontalization (Moustakas, 1994). Each statement or quote were tested for two requirements: is the statement necessary and sufficient for understanding the experience, and is it possible to code the statement (Moustakas, 1994)? If the statement was necessary and sufficient for understanding the experience, the statement was a horizon or code of the experience (Moustakas, 1994). The statements that were overlapping, repetitive, or vague statements were eliminated. The remaining statements were invariant constituents or codes of the experience (Moustakas, 1994). Clusters of meanings to the significant statements were developed into themes (Moustakas, 1994). The clustered statements and the theme were checked against the participant's interview record for a final identification using two requirements: expressed explicitly in the transcript and compatibility if not explicitly expressed (Moustakas, 1994). Irrelevant or not explicitly expressed statements and accompanying themes were deleted as they were not relevant to the participants' experience (Moustakas, 1994). I completed the description phase of the analysis to develop an individual detailed textural description of instances with verbatim examples from the interview transcript (Moustakas, 1994). The individual structural description was generated from the individual textural description of each participant to examine the emotional and social meaning of what the participant said (Moustakas, 1994). Interview questions are listed below and in Appendix C.

Table 1

Individual Interview Questions

1. Please tell me your name and more about yourself.
2. Please describe your relationship with a child with albinism.
3. How do you describe your child as a student?
4. Describe and explain the experiences of school for your child. SQ1
5. Describe the psychological barriers your child experiences. SQ1
6. Describe how physical barriers affect your child in school. SQ2
7. Describe and explain your child’s interactions with their peers. SQ3
8. Explain how school staff have helped your child to overcome barriers in the school. SQ2
9. Explain any practical techniques you feel educators need to know to help your child best. SQ2
10. Describe some common misconceptions about albinism. CRQ
11. Describe how albinism affects your daily routine as a parent. CRQ
12. Explain the affects of albinism on your child’s daily routine. SQ2
13. Please describe how the stigma of albinism affects your child mentally. SQ1
14. Describe how your child’s outward appearance affects family dynamics. SQ3
15. Explain and describe how albinism affects your child’s view of themselves. SQ1
16. Explain how you perceive your child as viewed by their peers. SQ3
17. Describe how you perceive society treat your child and family. CRQ

Questions one through three were introductory and helped to establish a rapport with the participant. Questions ten, eleven, and seventeen explored the relationship between albinism and family life. The remaining questions each looked at a different aspect of Erwin Goffman's (2009) social stigma theory and what affect it has on caregivers of CWA. Questions four, five, thirteen, and fifteen explored how the stigma of character affected PWA in school. Questions six, eight, nine, and twelve explored how physical stigma affected PWA in school. Questions seven, fourteen, and sixteen explored how the stigma of identity affected PWA in school.

Focus Groups

Focus groups provide a shared experience of people with similar characteristics (Creswell & Poth, 2018). Focus groups differ from individual interviews, where the focus is on the individual; focus groups help show any commonly shared themes among the participants. The focus group questions followed the same protocol as the interview questions. Four to five participants were randomly selected from interviews to participate in focus groups. According to Moustakas' method of analysis, focus groups took place virtually. The platform used was Microsoft Teams. The focus group was recorded using Microsoft Teams. The focus group was transcribed using Microsoft Teams. The data from the focus group transcriptions was analyzed for significant statements or quotes that explain parents' lived experiences or horizontalization (Moustakas, 1994). While reading the transcribed data, I memoed any thoughts or ideas to record any biases. Each statement or quote was tested for two requirements; is the statement necessary and sufficient for understanding the experience and is it possible to code the statement (Moustakas, 1994). If the statement was necessary and sufficient for understanding the experience, the statement was a horizon of the experience (Moustakas, 1994). The statements that were overlapping, repetitive, or vague statements were eliminated. The remaining statements were invariant constituents or codes of the experience (Moustakas, 1994). Clusters of meanings to the significant statements were developed into themes (Moustakas, 1994). The clustered statements and the theme were checked against the recorded transcript for a final identification using two requirements; expressed explicitly in the transcript and compatibility if not explicitly expressed (Moustakas, 1994). Irrelevant or not explicitly expressed statements and accompanying themes were deleted as they were not relevant to the participants' experience (Moustakas, 1994). I completed the description phase of the analysis to develop an individual detailed textural description of instances with verbatim examples from the focus group transcript (Moustakas, 1994). Structural descriptions were generated from the textural description for each participant to explore the emotional and social meaning of what the participant says (Moustakas, 1994). Focus group responses were coded and clustered while seeking emerging themes. Themes were cross-referenced to show what other themes were found across the data. Focus group questions are listed below and in Appendix D.

Table 2

Focus Group Questions

1. What are the reasons you decided to participate in this study?
2. Explain in detail your understanding of albinism. CR
3. Explain how you navigate as a parent caring for a child with albinism. CR
4. Explain and describe what you find particularly challenging for you as a parent as your child attends school. CR
5. Explain the process to receive assistance for your child to have an IEP in school. SQ2
6. Explain what it is like having or not having an IEP. SQ3
7. Explain what resources are available to parents of children with albinism. CR

8. Describe what resources the local school district has for mental health. SQ1
9. Describe your experience receiving assistance from other community resources for your child. SQ3
10. Describe your feelings receiving the diagnosis of albinism for your child. CR
11. Describe how having multiple children with albinism affects you. CR
12. Explain what you feel is needed for children with albinism to overcome the psychological barriers in education. SQ1

Question one is an introductory that helped to establish a rapport with the participant. Questions two, three, four, seven, ten, and eleven explored the relationship between albinism and family life. The remaining questions each look at a different aspect of Erwin Goffman's (2009) social stigma theory and what affect it has on caregivers of CWA. Questions eight and twelve explored how the stigma of character affected PWA in school. Question five explored how physical stigma affected PWA in school. Questions six and nine explored how the stigma of identity affected PWA in school.

Journal Prompts

Documents such as journal prompts provided additional primary source information regarding the participant's experiences as a caregiver of a child with albinism. Participant journals were utilized to provide other firsthand experiences of their accounting of events and allowed them more time to respond. The journal prompts focused on the participants' psychological barriers. Participants had at least two weeks to respond to the prompt. Journal prompts were analyzed using thematic analysis according to Moustakas' method of analysis. Journal prompts responses were investigated for significant statements or quotes that explained parents' lived experiences; memoing took place to ensure that any thoughts or biases were identified (Moustakas, 1994). Relevant passages or words were tested for two requirements; is the statement necessary and sufficient for understanding the experience and is it possible to code the statement (Moustakas, 1994). If the statement was necessary and sufficient for understanding the experience, the statement was a horizon of the experience (Moustakas, 1994). Those statements that were overlapping, repetitive, or vague statements were eliminated. The remaining statements were invariant constituents or codes of the experience (Moustakas, 1994). Next, clusters of meanings to the significant statements were developed into themes (Moustakas, 1994). The clustered statements and the theme were checked against the written response for a final identification using two requirements; expressed explicitly in the prompt and compatibility if not explicitly expressed (Moustakas, 1994). Irrelevant or not explicitly expressed statements and accompanying themes were deleted as they were not relevant to the participants' experience (Moustakas, 1994). I completed the description phase of the analysis to develop an individual detailed textural description of instances with verbatim examples from the journal prompt responses (Moustakas, 1994). Individual structural descriptions were generated from the individual textural description of each participant to examine the emotional and social meaning of what the participant had written (Moustakas, 1994). Journal responses were coded and clustered while seeking emerging themes. Themes were cross-referenced to show the themes found across the data of the other participant's journal prompts. The journal prompt question is listed below and in Appendix E.

Table 3

Journal Prompt Question

1. Please write in 500 words or more, recalling any incidences you have experienced as a caregiver of a child with albinism. Describe your emotional and mental state during the

incident.

Data Analysis

Data from interviews, journal prompts, and focus groups was synthesized into themes that captured the essence of the lived experiences of caregivers of CWA using textural-structural synthesis. Moustakas (1994) posits that during synthesis, reflection throughout the data analysis process helps create themes for the essence of the lived experiences. Reflexivity was shown in memos about participants' comments and thoughts during and after data analysis, as well as making sure personal biases were not reflected in the data to point towards a particular conclusion. Textural descriptions obtained from the individual interviews, focus groups, and journal prompts explained what occurred, and structural descriptions provided an explanation for how a phenomenon occurred (Moustakas, 1994). Emerging themes amongst participants were analyzed to identify connections between participants. Emerging themes were analyzed using passages and direct quotes from each participant. The textural-structural synthesis of all themes from individual interviews, focus groups, and journal prompts resulted in a composite, universal description of the phenomenon for the group (Moustakas, 1994).

Trustworthiness

Trustworthiness is defined as the accuracy of the data, interpretation, and method used to ensure the quality of a study (Connelly, 2016). In qualitative research, trustworthiness is addressed in several ways. According to Lincoln and Guba (1985), trustworthiness is outlined according to five criteria, credibility, dependability, confirmability, transferability, and ethical considerations (Connelly, 2016). Each of these factors can be followed. However, it is up to the reader to determine the study's trustworthiness.

Credibility

Credibility is the confidence that can be placed in the truthfulness of the research findings. The five criteria are the most important as they set the tone for all others and are often analogous to internal validity (Connelly, 2016). Credibility establishes whether the research findings represent plausible information drawn from the participant's original data (Connelly, 2016). Credibility is established by data collection triangulation (Nowell et al., 2017). To maintain validity, triangulation was achieved by utilizing multiple datasets that include individual interviews, focus groups, and journal prompts. The data from these sources was analyzed using the descriptive and pattern coding methods for emerging themes using Moustakas' modified Van Kaam approach. The use of multiple datasets avoids the risk of bias.

Transferability

Transferability is defined as the generalization of the study (Nowell et al., 2017). According to Lincoln and Guba (1985), transferability is only achieved using thick descriptions that vividly portray steps for application in other settings (Nowell et al., 2017). I used detailed descriptions of the participants, participant selection, data collection, and data analysis. Participant selection through purposeful sampling was limited to caregivers of individuals with oculocutaneous albinism (OCA). Given that OCA can affect any race, participants were from various ethnic backgrounds from various countries. Limiting the participant selection to those with OCA increased transferability. The use of thick, detailed descriptions allowed for the transferability of the meanings and essence of my study to other settings to determine the relatedness of other caregivers who are dealing with the psychological barriers children with albinism face (Nowell et al., 2017). Shared themes among the participant descriptions made the findings more transferable (Lincoln & Guba, 1985). Describing the details of the phenomenon required the use of multiple participant quotes, which allowed the reader to understand the phenomenon (Moustakas, 1994) more fully and clearly. In qualitative research, transferability is a suggestion that is up to the reader's interpretation (Nowell et al., 2017).

Dependability

Dependability is defined as the trust placed in the study. In qualitative research, dependability is built as the events unfold during the survey (Stahl & King, 2020). Dependability is accomplished through a research process that is logical, traceable, clearly documented and has gone through an audit performed by a credible committee (Stahl & King, 2020). Dependability in this research study was accomplished through participant sampling, interviews, focus groups, and journal prompts. Dependability was also established by inquiry audit and provided a documented step-by-step data collection and analysis process through Moustakas' modified Van Kaam approach.

Confirmability

Confirmability is the degree to which other researchers can confirm the research study findings and accurately represent the data (Connelly, 2016). According to Lincoln and Guba (1985), confirmability is established when credibility, dependability, and transferability have been achieved (Connelly, 2016). Additional ways to show confirmability include using markers for theoretical, methodological, and analytical choices to aid in understanding the decisions made (Nowell et al., 2017). Confirmability in this study was established by making my biases known through reflexivity. I am in the same position as the participants; therefore, it was important to remain neutral. I empathized with the participants and their children, which can constitute biases. An application was submitted to Liberty IRB for approval. The study proceeded after Liberty University's IRB application was approved. A detailed audit trail was maintained during data collection, analysis, and writing of the final report. Triangulation was achieved by utilizing multiple datasets that included individual interviews, focus groups, and journal prompts Memos about participants' comments and thoughts during and after data analysis were done to ensure personal biases were not reflected in the data to point towards a particular conclusion. To successfully gather an unbiased description of the data during data analysis, I bracketed and was extremely mindful not to let my biases skew the interpretation.

Ethical Considerations

Upon Liberty University IRB approval, recruitment and data collection commenced. Ethical considerations for this study included obtaining participant access, informed consent, informing participants of their right to withdraw from this voluntary study, the confidentiality of the participants, use and storage of data, and risks and benefits.

Permissions

The study did not occur in a physical setting; however, permission was obtained from Liberty University's Institutional Review Board (IRB), given the generic environment. An application was submitted to Liberty IRB for approval. Refer to Appendix A for the Liberty IRB application. The study proceeded after Liberty University's IRB application was approved.

Other Participant Protections

Participant access was obtained through public channels via social media for individuals with albinism. Participants informed consent was received by notifying them of the critical elements of the study and their involvement via a consent letter. Once the informed consent was signed, all collected data was stored securely on an encrypted and password-protected drive. Participants were fully aware of the right to withdraw from the study at any time. Data will be securely kept and then destroyed after three years. Participants' identities remained confidential via the use of aliases. The risks were also discussed with the participants, including retelling a traumatic event in their life. Additionally, participants were made aware of the benefits of the study, which included providing insight into the psychological barriers of individuals with albinism to help guide instructional strategies for primary school-age students.

Summary

The purpose of this transcendental phenomenological study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. The study utilized a transcendental phenomenological research design. The research questions, setting, participants, positionality, and procedures are provided. This transcendental phenomenological study utilized Moustakas' modified Van Kaam approach. This study added to the body of literature because it has yet to be studied. Little to no research examines the psychological barriers children with albinism face. The data collection utilized primary sources, including individual interviews, a focus group, and journal prompts. Trustworthiness and ethical considerations were discussed. The results of this study could impact how school officials provide support for students with albinism. This study sought to shed light on the psychological barriers to education caregivers face as their child navigates public education.

CHAPTER FOUR: FINDINGS

Overview

The purpose of this transcendental phenomenological study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. Data analysis was completed using Moustaka's modified Van Kaam approach (1994). Chapter Four introduces each participant. The participants' lived experiences are provided in the results section of this chapter. The responses to each research question are discussed using the thematic findings discovered in this study.

Participants

The participants for this study were all caregivers of children with albinism attending general education classes. The participants were recruited by purposeful sampling. Pseudonyms were applied to all participants to ensure confidentiality. Eleven participants were recruited for this study. The age range of the participants was 28 to 53 years old. All participants are United States citizens. Five participants were of African/African-American descent. Six participants were Caucasian. Six participants were in the Southeast region of the United States. One participant was outside the United States. One participant was in the Northeast region of the United States. Two participants were in the Midwest region of the United States. One participant was in the Western region of the United States. Refer to Table 4 below and Appendix F for participant information.

Candice

Candice, an African-American single mother of two, resides in the United States Midwest. She has one son in elementary school with Oculocutaneous Albinism Type 2. Candice had a rocky start as a parent of CWA; however, after finding spiritual support in her community, she has grown mentally and spiritually to help her son overcome educational obstacles. Candice described her experiences as trial and error with no instruction manual for parents of children with different issues. She wants the best for her son and expresses that her experiences have been difficult; however, she firmly believes in having a positive mindset regarding how people view herself and her family.

Denise

Denise, a Caucasian married mother of four, lives in the Northeast region of the United States. She has one son in middle school with Oculocutaneous Albinism type 4. Denise felt early on that her son would be ok upon learning of his diagnosis. She credits her positive outlook on things to making connections early with intervention services and connecting with other families in the albinism community. Denise is very involved in fundraising and increasing awareness of albinism. She and her family are members of the albinism community; however, they do not let albinism define them as their primary identifier.

Jessica

Jessica, a Caucasian married mother of fraternal twins, has one daughter with Oculocutaneous Albinism Type 1. Jessica is residing in the Midwest region of the United States. Her daughter is in elementary school, where she is the only student with albinism in her school. Jessica has had nothing but great experiences as a parent of a CWA. However, she knows there is a harsh side to society, and she wants to prepare her daughter for what may come. Jessica strives to provide her daughter with all the necessary resources by moving specifically to a school district based on the available resources. She credits her daughter's academic success to her fantastic vision support staff, who have been with her daughter for five years.

Kate

Kate, a Caucasian married mother of two, lives in the Southeast region of the United States. She has two sons in elementary school who have Oculocutaneous Albinism type 4. Kate’s experiences as a parent of a CWA started with a great deal of fear when her oldest son was diagnosed; however, she found an extreme amount of support through organizations such as NOAH, the National Organization for Albinism and Hyperpigmentation, that have helped her along her journey. Kate also creates a positive outlook on albinism through communication with adults living with albinism. Her journey as a parent has motivated her to start a research program with NOAH to help her and other parents learn more about albinism. Therefore, Kate strives to expose her sons to all available resources to help them succeed.

Rachel

Rachel, a Caucasian married mother of two, currently resides in the Southeast region of the United States. Her daughter has Oculocutaneous Albinism type 1 and is in elementary school. Due to her job requirements, Rachel and her family move often and have had their fair share of different states and regulations regarding support for her daughter. She has gone from an abundance of services for her daughter, where she is thriving, to no services; however, that has not stopped her from fighting to get her daughter the appropriate services she needs. Rachel wants her daughter to have the same opportunities as everyone else despite her albinism.

Rebecca

Rebecca is a Caucasian married mother of three. She has a son who has Oculocutaneous Albinism type 2 and is in elementary school. Rebecca currently resides in the West region of the United States. Her son’s diagnosis was a shock, given that she did not know any family members having the same condition. Rebecca says her overall experience has been positive. However, given his limited vision, she worries about her son socially. Therefore, she seeks to surround her son with people who have his best interest in mind.

Rhonda

Rhonda, an African-American single mother of five living in the Southeast region of the United States, has two sons with Oculocutaneous Albinism type unknown. Rhonda has one son who is in high school, and the other is in college. Rhonda says her experience as a parent of a CWA has been different; her experiences with her older son taught her what to expect and helped her with her younger son. Rhonda has a great relationship with her sons and uses humor as a form of bonding. Rhonda and her family are very protective of her sons, and she makes sure she sets a positive example for her sons to follow as they get older. Rhonda is open-minded when encountering society and is more than willing to help educate those unfamiliar with albinism.

Sarah

Sarah, a Caucasian married mother of two who lives in the Southeast region of the United States, has a daughter with Oculocutaneous Albinism type 2 and a son with Oculocutaneous Albinism type 1A, both of whom are in college. Sarah and her husband opened their home to their children when they were toddlers and are open about the fact that no one shares genetics in their home. Sarah did not limit any activities for her children; she exposed them to everything they wanted to try and aimed to teach them to be strong and ignore society's insensitivity. She seeks to ensure that her children are treated fairly.

Sasha

Sasha, an African-American married mother of two living in the Southeast region of the United States, has a son in middle school with Oculocutaneous Albinism type unknown. Sasha's parent experience has been filled with being proactive and ensuring her son has the same experience as his peers. From the moment her son was diagnosed, Sasha took the necessary steps to ensure her son was happy, accepted, and had the necessary accommodations to be successful. Despite the constant advocacy she has to do to ensure her son has a normal upbringing, Sasha's experiences have not caused her to view society negatively.

Stacy

Stacy, an African-American married mother of one living in the Southeast region of the United States, has a daughter in elementary school with Oculocutaneous Albinism type unknown. Stacy feels her experience as a parent of a CWA has been really tough due to the immense lack of albinism awareness where she lives; therefore, Stacy feels it essential to learn as much as possible about albinism in order to help educate others on the condition and how to react when approached in society. Stacy wants to prepare her daughter correctly. Therefore, she researched much information to be the best parent for a CWA.

Zuri

Zuri is an African-married mother of three residing outside the United States. She has a daughter in elementary school with Oculocutaneous Albinism type unknown. Due to cultural differences, Zuri’s experience as a parent of a CWA has been one of constant struggle for safety and a sense of normalcy for her daughter. Zuri strives to provide the best for her daughter and urges that she is treated the same as her unaffected siblings. Despite how society reacts to her when she is in public with her daughter, Zuri does not let society cause her to feel depressed or ashamed.

Table 4

Participants

Participant	Age	Ethnicity	Marital Status	Region	Number of Children with OCA	Child's Age	Type of OCA
Candice	35-40	African American	Single	Midwest	1	5-10	Type 2
Denise	40-45	Caucasian	Married	Northeast	1	10-15	Type 4
Jessica	30-35	Caucasian	Married	Midwest	1	5-10	Type 1
Kate	35-40	Caucasian	Married	Southeast	2	5-10 and 0-3	Type 4
Rachel	35-40	Caucasian	Married	Southeast	1	0-3	Type 1
Rebecca	35-40	Caucasian	Married	West	1	5-10	Type 2
Rhonda	45-50	African American	Single	Southeast	2	15-20 and 20-25	Unknown
Sarah	50-55	Caucasian	Married	Southeast	2	15-20	Type 2 and Type 1A
Sasha	30-35	African American	Married	Southeast	1	10-15	Unknown
Stacy	25-30	African American	Married	Southeast	1	5-10	Unknown
Zuri	30-35	African	Married	Outside the US	1	5-10	Unknown

Results

The thematic results of this study describe the lived experiences of caregivers of children with OCA who attend general education classes. The modified Van Kaam method by Moustakas (1994) was used to identify themes according to this study's theoretical framework. The participants completed a writing prompt and individual interview and participated in a focus group discussion. The themes are the caregivers' lived experiences, as seen in Table 5 and Appendix G.

Table 5

Themes & Subthemes

Theme	Subtheme
Emotional Challenges	
	Unknown Future
Parenting Adjustments	
Lack of Awareness in Society	
	Advocating for Awareness
School Experience	
	Teacher Interactions
Self-Image	
Academic Success	
Daily Routine Adjustments	
Family Dynamics	
	Cultural Awareness
Peer Interactions	

Emotional Challenges

Many participants in the study shared experiences of emotional challenges equating to a paradox of emotions as they parent their child(ren) with OCA. Participants' paradoxes included guilt, disbelief, immense love, shock, devastation, constant worry, helplessness, need for protection, second-guessing, and stress. Candice shared, “When I gave birth to my child and saw him for the first time, I was shocked. I was not educated on the condition and automatically thought I did something wrong during my pregnancy. I held him in disbelief and fell in love." Rebecca echoed Candice's feelings and included, "I worry, is he being treated nicely at school? Are they including him? I definitely have concerns about whether he can see his friends across the playground." Jessica added, "I know she will probably struggle with her self-image like everybody else. And so that is hard knowing that it may affect her negatively at some point." Kate agreed with Jessica's concerns, "I mean, for me, going into kindergarten was scary because even though I knew he would do quite well academically, I think the bullying and the social aspect is a significant part." Rhonda elaborated on Kate's feelings of concern and expressed,

> I found out that my son had attempted to commit suicide unsuccessfully several times. As a mother, I was devastated and blamed myself because I had no idea. I could not imagine living without him. It made me more protective of all of my children.

Candice emphasized Rhonda's feelings of heartache and stated,

> My child has also isolated himself to avoid bullying. It has also been a struggle for me because it is hard to watch your child experience different emotional traumas and not know how to explain why others act the way they do.

Zuri said, "I am worried that she will be the only person caring for her skin." Stacy expressed, "Honestly, it has been a lot; one challenge I did have was in kindergarten last year with her; one of her teachers did not want to follow the IEP." Sasha agreed with Stacy, saying, "One of the biggest challenges for me is making sure the teachers do their part because I am not there anymore." Rachel elaborated on Sasha's feelings and stated, "It has been difficult because the schools are reluctant to work with us, and that is incredibly disappointing because I know my child is not the only visually impaired kid around here." Given the rarity of albinism, participants worry about how society will treat their child(ren) and if they are providing the necessary tools to tackle society's ignorance concerning albinism.

Unknown Future

The rarity of albinism gave rise to the unknown future sub-theme. The sub-theme comprises worrying about the psychosocial aspect, the educational setting and taking proactive steps codes. Kate shared her reaction when receiving her child’s albinism diagnosis in which she expressed feelings of fright and sadness, “I feel like initially it was really scary because I did not know anything about it, and I did not know what legally blind meant.” Sasha agreed with Kate, stating, “It was very scary; I did not like it; I did not know what to do; I did not know what it came with.” Denise elaborated on Sasha’s thoughts and added, “You think, what can we learn more, how can we understand this, and what can we do to make him the most successful.” The limited resources available to community leaders, school administrators, and families aided in the sub-theme of an unknown future. Candice disclosed, “When I first had him, I was told he may never be able to drive and different stuff.” Rebecca elaborated on Candice’s experience and shared, “I was saddened by it; when they are babies, you are devasted because the future you thought they would have is going to look different, but you get through it.” Jessica conquered with Rebecca and shared, “Up until now, she does everything everybody else does; at some point, her friends are going to learn how to drive, so we will see how that goes.” Rachel agreed with Rebecca and went on to equate the feeling to that of grief, “Scared of the unknown future and grieving the loss of the life that you thought your kid would have.” The anxiety expressed by the participants reflects the phenomenon of the unknown future parents' experience while parenting a CWA.

Parenting Adjustments

Parents innately adjust their lives when they have a child, however, participants shared numerous adjustments outside the norm. “Rachel shared, “You care about the sun when you have a baby, but you care about the sun differently when your baby has albinism. Concentrated thought goes into what we do; we are much more intentional about everything we do and buy”. In agreement with Rachel, Stacy shared, “We have just to be more strategic than we used to be.” Sasha elaborated on Stacy’s remarks: "I have to have tinted windows. I have to watch out for what time of day we usually go out.” Zuri added, “On vacation, I choose places on the greener side.” Participants expressed adjustments that affect not only them but their entire family. Jessica divulged, “I used to want to take them places all day, but now we are getting used to a slower routine in the summer.” Kate elaborated on Jessica’s experience, “In order for us to go anywhere, we do have to stop and make sure that everyone has sunscreen on and pay attention where we sit.” Rhonda disclosed, “I am their transportation, so I have to change my schedule to fit their schedule.”

Lack of Awareness in Society

The participants shared multiple experiences depicting the lack of awareness in society. Jessica stated, “The thing that bothers me the most when we go places is she does get stares when she has her cane.” The lack of awareness in society was a direct result of the rarity of albinism and the limited resources available in communities. Stacy expressed, “There are a lot of uneducated people. So, I have had several incidents where I have gotten dirty looks and side comments.” Kate also shared, “This woman commented to raise his hat, he cannot see, and I just sort of brushed it off.” Rebecca stated, “They would comment on his eyes shaking fast; I would take that hard and get a little defensive about it.” Sarah shared a similar experience with her son:

"People would come up, touch his hair, his skin; he did not like it, I did not like it or say he does not have full albinism, his eyes are not pink." Misconceptions and stereotypes surrounding albinism aided in the insensitive interactions participants had with society. Zuri mentioned, "I was praying in the holiest of places, and this lady sat next to my daughter and proceeded to ask her who I was to her and her brothers; she could not accept I was her mother." The sentiment of colorism was heightened when Rhonda shared her experience with a woman at the grocery store, "This Caucasian woman grabbed the cart and refused to let me proceed. She looked me in my eyes and demanded that I tell her whose baby I had." Candice further elaborated on Rhonda's experience by sharing, "Out in public was a struggle for me due to people staring and asking if he was adopted." The lack of awareness in society and the experiences the participants expressed also correlated to members of societies who assumed the right of entitlement to the participants' private lives. Rachel summed up societies' sense of entitlement best;

> At some point, you want to say it is not your business, leave her alone. She is doing the best that she can. However, there is constant second-guessing, naysaying, and strange looks. It is why we do not go to theme parks anymore because it is so hard to do it with a kid that's already got a vision problem, and then now to add in not knowing what is going to be said is not worth it, we will go somewhere with fewer people.

Advocating for Awareness

The participant's accounts of societal interactions gave rise to the sub-theme advocating for awareness. The sub-theme advocating for awareness was present amongst participants in the individual interviews and focus group discussions. The sub-theme advocating for awareness is a combination of three codes, awareness in education, awareness in society, and personal awareness. Denise stated, "We will teach people about this and teach people what it is and educate people about it." Sarah carries albinism information cards to help combat society's lack of awareness; "People just do not think about what they or say sometimes, so I carry albinism information cards and hand them out as needed." Rhonda expressed, "I could see my son's face melt in agony; I told him later that sometimes you have to decide if you are going to educate people or ignore them." Zuri exclaimed, "I have to fight the white population and I have to fight African Americans to prove I am her mother. Upon having a CWA, participants worked to improve their personal awareness in order to serve their child(ren) best. Stacy mentioned, "I had to research a lot to know as much as I do now; I had to research everything to be the best parent I could be to a child with albinism." Rachel agreed and shared, "We attended a NOAH conference and worked with an organization that provides summer camps and ways to get your kids involved in things at home." Many participants visit their child's class at the start of the school year to teach the students about albinism. Sasha mentioned, "I had to advocate for him with his teachers to ensure he experiences the same as everybody else and not singled out." Rebecca is preparing to speak with her son's class this upcoming school year regarding his albinism. "Get ahead of it so it is not something secretive, and by the time they are older, realize it is just Brian; he has albinism," mentioned Rebecca.

School Experience

The theme of school experience was split amongst participants, many of the participants shared positive school experiences for their children that included adequate resources, support staff, and support from administrators. Jessica expressed, "We moved to the school district where we live for the resources that they have available." In agreement, Candice stated, "I moved him to another school that really helped me understand different things and he was also placed in classrooms where he felt he was more included." Zuri further concluded, "I sent her to a

Caucasian-based school so she does not feel very different. She does not experience any bullying." Kate, Denise, and Rebecca added positive experiences and credited easy access to resources as the determining factor. Rebecca mentioned, "For me, it was super easy. My son started going to a preschool for students with special needs through the county." An opposing school experience was found to be a result of a lack of inclusion and support from school administrators, staff, and peers. Stacy stated, "When I was advocating for her, the administration just did not do anything about it, even though I was working there as a school administrator, so it was a struggle." Sarah shared a similar experience, "Kids called him a white Chinese and said he needed to go back to China. He spent time in the band room to escape the kids." Sarah further disclosed, "They kicked him till he had bruises on his legs. I reported this to the school, but the school did nothing." Sasha elaborated on Sarah's experiences and stated, "In elementary, I had to work hard for accommodations; it was not diverse; he looked very different, so some kids would sometimes call him Casper and say he had French fry hair." The lack of inclusion was found to be directly related to school experience as reported by participants. When asked what was needed to help address the psychological issues in many schools that had negative experiences, focus group participants expressed a need for a support group for students. Rachel expressed, "I will never live her experience, but if she can talk to somebody who does, I think that will help her from an all-around psychological perspective."

Teacher Interactions

Teacher interactions emerged as a sub-theme from the school experience theme. The sub-theme of teacher interactions was a combination of three codes; teacher knowledge of student needs, teachers lacking knowledge to support student needs and teachers becoming agitated with students. The interactions with teachers served as a contributing factor to the school experience.

Participants noted positive experiences when teachers knew student needs and were welcoming and inclusive. Jessica best summarized teacher interaction when she characterized her interactions with her daughter's teacher as “amazing” and “very supportive”. She shared, “She (teacher) is a really good fit for my daughter because that is what she needs to be pushed and motivated and she has done really well in general education.” Before her daughter was in general education, Jessica’s daughter was in an inclusion classroom; the trust she had in her daughter's teacher and the support her daughter received allowed her to be able to have a positive school experience. Jessica further expressed, “Her orientation and mobility and teacher for visually impaired specialists are awesome, I trust them with anything, they have walked us through everything.” However, when support is not present from the teacher, it can lead to a challenging experience for the student and the parent. Candice shared incidents of teachers not supporting her son, getting agitated with having to provide him accommodations in class and allowing racial slurs to be directed toward her son with no teacher intervention. Candice exclaimed, “One of the children said he is white, not one of us, and the teacher said or did nothing, and the other kids joined in pointing and laughing.” Stacy conveyed similar experiences of teachers “questioning” her request for accommodations by stating, “Teachers feel like if she is great academically, why does she need certain things.” Rebecca recalled her interactions with her son's support staff have her feeling “indifferent” as she does not feel her son’s needs are being met, only checking a box to say he was serviced. “I feel like she just kind of has to meet her quota of hours spent with him, so she is trying to find things to do with him,” Rebecca iterated. Overall, the interaction with the teachers sets the tone for the school experience given that the teachers and support staff are responsible for providing services to the student and communicating with the parent.

Self-Image

Self-Image describes how the participants' children viewed themselves while attending school. The theme of self-image connects to the parenting challenges participants encounter while caring for children with OCA. Participants explained the relationship between albinism and mental health. Jessica mentioned, “She thinks having albinism is the coolest thing ever.” Zuri added, “She does not feel any different; she is a happy and very strong child mentally.” Self-image was indicative of the school experience and family upbringing. Stacy conveyed, “At her predominately black school, she got many questions, so for a while, she felt like she needed darker skin so she could be pretty, and that affected her.” Rachel exclaimed, “We have been very intentional about treating albinism like blue eyes, and she accepts it with open arms.” Participants reported positive self-image accounts once their child(ren) made a core group of friends. Denise expounded by adding, “My son had some self-confidence issues, but now he has a peer group and is much more confident.” Participants with older children mentioned how teacher interactions affected their child’s self-image in hopes of trying to fit in with other students. Sarah stated that her daughter tried to use self-tanning lotion after coaches made comments about her “sticking out” in team photos. “Coaches would say you need to get a tan; you cannot stand out like that, so we tried tanning lotion; it was annoying, but she is pretty strong,” Sarah reported. Participants described positive self-images based on how they handled albinism within their family dynamics. Candice conveyed that her son struggled with self-image due to constant bullying and racial slurs from peers; however, how she approached the issue helped. “James started to question why he looked like this; I did not know how to explain it, so I took race out and explained it, and then he was ok,” reported Candice. Self-image issues were noted to be more apparent once participants had children getting ready to go to middle school; at younger ages, self-perspectives are still developing. Kate mentioned, “He knows he has albinism, but it does not come up that much. I do not know that he has a strong perspective yet on him for himself.”

Academic Success

The theme of academic success was comprised of the requirement for accommodations, the need for additional support staff, the use of assistive technology, and sun protection. Sarah said, “They use iPads to help them overcome physical barriers.” Rebecca stated, “The additional support staff helped tell me what my son needed to be most successful in class.” Stacy said, “The school staff is wonderful; they have helped her maneuver the school.” In agreement, Denise added, “Students are not allowed to carry backpacks; however, my son can, so his vision teacher makes sure he can access his locker and has everything.” Candice, whose son struggled with behavior issues from bullying and lack of emotional support in his previous schools, further elaborated on Denise’s experience and shared, “The staff started an intervention plan where the teacher works with him individually to keep him calm and walk him through different coping mechanisms.” During this study, participants voiced that teachers advocating for students aided in academic success. Sasha expressed, “his visually impaired teacher advocates a lot for him and demonstrated things needed in the classroom for him.” The need for accommodations was found connected to receiving an IEP. Participants were split on the use of the IEP due to the process each went through to get an IEP for their child(ren). Kate stated, “We have been quite lucky in getting connected pretty early to all the early learning; they both have gotten any services they need.” Within the focus group, one participant stated that the process was rough and affected academic success. Rachel shared, “We are not having a good run, accessors did not think she needed additional support, even though her ophthalmologist says she does, which is incredibly disappointing.” The culmination of all codes for accommodations requirements comprises the participants' experiences of academic success playing a role in school challenges participants faced when raising children with OCA.

Daily Routine Disruptions

The theme of daily routine disruptions is the adjustments needed for CWA participants to succeed in the classroom. Participants indicated daily routine disruptions consisted of sunscreen application, adjustments to activities, help with navigation, and therapy. Rebecca explained how her son must leave class to get sunscreen applied before going outside. Rebecca mentioned, “He likes going to the nurse's office; the teachers send him before PE and in the afternoon.” Kate added, “Bradley needs sunscreen. We have had to work with the school to ensure they know every time before he goes outside.” Jessica explained how her daughter’s visual impairment affects her daughter’s daily routine, saying, “Towards the end of the day, I limit her activities; she gets eye fatigue and headaches; that is when she may trip, fall, or run into something.” Stacy agreed, adding, “She loves soccer but cannot play outside, so we must find alternatives.” Participants with multiples or no other unaffected children reported that daily disruptions are not disruptions but the norm due to knowing nothing else. “Routine-wise, we try not to make a big deal out of anything; her cane is a fourth thing on the list,” Rachel exclaimed. Along with daily disruptions are the necessary adjustments required for physical and mental health. Candice stated, “He started therapy in kindergarten, and he is now in middle school; he has also been in ABA therapy for the past six months to help with other issues.” Participants stated that therapy was provided at or outside the school. Rhonda placed her sons in therapy following revelations her older son made regarding bullying and suicide attempts. “It made me more protective. I have both my sons in therapy," stated Rhonda. The requirement of therapy disrupts children's day and parents must make time to address the deficits in their child's lives.

Family Dynamics

The theme of family dynamics was noted as another key theme in this study. Participants indicated family cohesion as a key component that did not affect family dynamics. The ability of individuals with OCA to identify with a certain race or group affects all members of the family. All participants indicated family cohesion during individual interviews. Family cohesion within the immediate family of participants was not affected by OCA. Jessica stated, "She did not look much different than us. She is much fairer than we are, but she does not stick out a whole lot either." Kate declared, "From a family dynamics place, not obvious." Denise agreed, "Albinism has no huge impact on family dynamics." When PWA belongs to families of a darker complexion there can be issues with family dynamics, however, participants indicated no issues. Sasha mentioned, "Albinism does not affect dynamics at all." Sarah elaborated on Sasha's experience by sharing, "Our whole family accepts both of them, both sides." No noted issues were present within the immediate family; however, some were present with the extended family, due to a lack of understanding of albinism. Rhonda mentioned. "They are not treated any different, but family members are apprehensive about outdoor activities because they do not want the responsibility." Issues with extended families can arise; however, when a patriarch of the family accepts a PWA, members of the extended family are more accepting. Rachel shared, "Once Ally was diagnosed, my family said Uncle Luca probably had it too, and there was immediate acceptance on my side because he was like the family patriarch." However, some still may not, as was the case for one participant. Candice reported, "My son's father did not acknowledge him as a human being. I took him to his great uncles, and he explained to me that he was definitely his child because they have albinism on their side of the family."

Cultural Awareness

Cultural awareness within family dynamics was noted amongst two of the eleven participants. The lack of cultural awareness caused issues with family dynamics. Zuri indicated, "In terms of family, not many of my family members have access to her. And I have had very close family members of mine, try to give her sacrificial things." The lack of cultural awareness surrounding albinism was also present in Rachel's extended family when her daughter was born, "My husband's side is a traditional Italian family; they are very kind and nice people, but there is just that little bit of distance now," exclaimed Rachel.

Peer Interactions

The interaction with peers played a role in the psychological barriers the CWA faced which also dictated the emotional challenges a participant would endure. Participants noted that their peers accepted and supported CWA when peer interactions were positive. Jessica's experience best summarizes positive peer interactions that lead to peer acceptance and support. "I think that it has been really sweet to see her friends and how they treat her. How they interact with her, they will say let us do it in the evening; it is easier for Phoebe." However, it became evident that not all attention from peers is taken as thoughtfulness. Zuri stated, "Next to her was a beautiful, darker-skinned little girl, and usually those are the kids that envy her." Participants stated that once their CWA found a close group of friends their self-confidence increased and were more social. Sasha stated, "I separated him from his elementary school friends; that was when the bullying increased, so I moved him back to where his friends were, and he engaged in social butterfly." Rhonda added, "My younger son interacts with his friends through video games and meets his friends at the Rec Center to play basketball." Sarah indicated, "Gabby has a small group of close friends; she is my social butterfly, while Jake has two or three friends he is close with."

Outlier Data and Findings

Unexpected findings inconsistent with the rest of the data are considered outliers. Major unaligned findings are reported in this section. This study identified one outlier during the data collection and analysis phase. Outlier data was found with Zuri in the theme of cultural traditions threatening safety.

Cultural beliefs threaten safety

One participant noted the theme of cultural traditions threatening safety. Zuri indicated that the society she interacts with has different cultural beliefs in terms of albinism and those beliefs threaten her daughter's safety. Zuri's experience with society is a constant fight and has caused her to be on guard and suspicious of intentions when it comes to her daughter's safety. Zuri explained, "So in terms of freedom, she has less freedom than her brothers, and that is for security. On this side of the wall, people think that albino people have superpowers. So, wherever she goes, I have a camouflage bodyguard with her."

Research Question Responses

This research study consisted of one central research question and three sub-questions. Each research question in this study aligned with the stigma model by Erwin Goffman (2009). The responses to each research question and the themes that answered each research question are included. In-vivo participant quotes are provided to support the responses to the research questions. A table of thematic alignment to each research question can be found below in Table 6 and Appendix H.

Table 6

Research Question Responses

Theme	Subtheme	Research Question
Emotional Challenges		Central Research Question
	Unknown Future	Central Research Question
Parenting Adjustments		Central Research Question
Lack of Awareness in Society		Central Research Question
	Advocating for Awareness	Central Research Question
School Experience		Sub Questions 1
	Teacher Interactions	Sub Questions 1
Self-Image		Sub Questions 1
Academic Success		Sub Question 2
Daily Routine Adjustments		Sub Question 2
Family Dynamics		Sub Question 3
	Cultural Awareness	Sub Question 3
Peer Interactions		Sub Question 3

Central Research Question

The central research question for this study is, what are the lived experiences of parents of children with albinism in school? This study reveals three themes experienced by participants: emotional challenge, lack of societal awareness, and parenting adjustments while caring for a CWA. Parents caring for CWA experienced emotional challenges from the day their child(ren) was born. These emotional challenges included feelings of shock, fright, heartache, devastation, sadness, and helplessness. Participants are bombarded daily with these challenges while also trying to care for their families and themselves. Rhonda declared, “There could be an attitude because of something somebody had said to them. So, many times, it becomes difficult as a mom to pry information out of your child.” Participants shared experiences of various emotions that make parenting a CWA stressful and difficult at times, not due to their condition but due to the actions of others and the lack of information available to parents. Rhonda further stated, “It is not hard parenting a child with albinism, but hard for the world to accept those with albinism.” Upon learning of their child(ren)’s albinism diagnosis, participants feared an unknown future due to the lack of information available. Rebecca responded, “Those initial moments of when they are a baby, and you are so devasted because the future that you thought they would have is going to look different; it is an adjustment.” Several participants shared the experience of emotional challenges as the participants' child(ren) grew older; the emotional challenges changed from overwhelming to manageable. Rebecca further stated, “When we realize it is okay, just different, not bad, we will get through it together.”

Participants felt the emotional challenges were related to the lack of societal awareness. The lack of societal awareness presented itself in the form of insensitivity, colorism, and invasion of privacy. Insensitivity from society was found to be related to the lack of awareness found in society and schools. Comments and stares from society made parenting a CWA emotional. Stacy described her encounter with society and how interactions with society are unpredictable. “They do not understand what albinism means and they feel like I went and adopted this white child, and she should be with her white family”, Stacy exclaimed. Participants reported experiences with a society that involved an invasion of privacy in the form of questions regarding paternity or unwanted touching. Candice reports, “One nurse asked if my child’s father was Caucasian.” Sarah also stated, “Our son was sitting at the end of the table, and an older lady walked past, and one of them brushed his hair, and my son was really annoyed; he did not like it, and I did not like it.” Participants also reported parenting adjustments that were needed to accommodate their new normal. Parenting adjustments involved sunscreen application, helping navigate the environment, and limiting routines due to albinism. Many participants limit activities and sun exposure. Rachel stated, “Concentrated thought goes into what we do; we check UV rating before going outside every day to see how high it is going to be and when it is going to be too high for her to be outside.” Participants indicated that sunscreen application was a new standard and required adjustment for their routine. Denise shared, “I make sure he has sunscreen and what he needs, which also gives him more tools to be independent.” CWA have visual impairments that vary in degree from manageable to legally blind. Participants noted the requirement to be more aware of their surroundings in new environments to help CWA navigate their new surroundings. Kate added, “If we go somewhere new, I am always queuing them up, a lot of verbal cues."

Sub-Question One

What affect does albinism have on a person’s character/mentality in school? Sub-question one explored and identified the affect albinism has on a person’s character or mentality. This study found that school experience, teacher interactions, and self-image affect a person's character/mentality in school. Participants noted a positive school experience when resources were available, and a high degree of inclusion was incorporated into the school environment. Zuri shared, “Her teachers joke with me about her being blonder than them, but other than that, we do not have any issues.” Negative school experiences were noted to be related to the lack of inclusion in the school environment, resulting in bullying. Candice noted a negative school experience when her son was in an environment that was not conducive to his success. “I always knew he was a bright child, but the emotional trauma he experienced through the building from students being uninformed of his condition took a toll on him,” stated Candice. Teacher interactions also affect a person’s mentality in school; Candice reported, “He has stated that he felt certain teachers did not like him and were giving him a hard time. I know it is realistic because teachers can get agitated from having to do extra stuff for him.” Self-image reports from participants showed a correlation to the school experience, easy access to resources, and inclusion. Some participants indicated some issues with self-image; however, once participants' children were more confident with their condition, issues lowered. Sasha mentioned, “In elementary school, he wondered why he looked different; however, he got to a good point where he accepted being different, and he is doing much better now.”

Sub-Question Two

What affect does albinism have on a person physically in school? In this study, participants stated that their CWA required accommodations for academic success. Academic success was found from participant experiences, which involved the need for additional support staff, the use of assistive technology, and sun protection. Participants voiced that teachers advocating for students aided in academic success. Candice reported, “Sometimes teachers can be a great help, and sometimes teachers can make them feel handicapped; sometimes they can make them feel invisible and not capable of communication, so I have to teach my sons how to communicate with their teachers to make their needs known.” Participants with children who use an identification cane (ID)cane to navigate their environment indicated a need for additional support for academic success. Sarah shared, “Their vision teacher would leave her classroom and check on them after they moved to different sections of the building.” During the study, participants also indicated that daily routine adjustments affected their CWA physically in school. Denise mentioned, “His backpack is really, really big, so he is always carrying way too many things, he knows like it is just part of his routine.” Sasha added, “90% of the time, lighting in the classroom affects him; he had to learn different ways to get around in the classroom.” Along with daily disruptions are the necessary adjustments required for physical health. Jessica added, “Phoebe started Braille in first grade; she meets with her intervention specialist twice weekly.”

Sub-Question Three

What affect does albinism have on a person’s ability to identify with a particular group/race/religion? During the study, participants indicated that albinism does not have an affect on family dynamics within the immediate family. The ability of individuals with OCA to identify with a certain race or group affects all members of the family. All participants indicated family cohesion during individual interviews. Stacy reported, “My entire family is not affected because I have two uncles and a few cousins with albinism, so when we are all together, it does not affect family dynamics.” However, there were some issues with extended family for one participant due to cultural awareness. Rachel shared, “When my in-laws came to visit, my father-in-law looked at my husband straight in front of me and said, are you sure this is your daughter?” In the educational setting, albinism did not affect a person's peer interactions. Participants revealed that their CWA are treated the same as everyone else and are accepted and supported by their peers. Sasha stated, “Oh no, it does not affect the dynamics at all, and he is a social butterfly.” Participants stated that once their CWA found a close group of friends their self-confidence increased and were more social. Sarah mentioned, “Gabby has a small group of close friends; she is my social butterfly, while Jake has two or three friends that he is close with.”

Summary

Chapter Four included the participants' lived experiences as caregivers of a child with albinism. Data analysis using Moustakas modified Van Kaam (1994) method identified nine themes (Moustakas, 2009). The nine themes identified include emotional struggles with the sub-theme unknown future, parenting adjustments, lack of awareness in society with the sub-theme advocating for awareness, school experience with the sub-theme teacher interactions, self-image, academic success, daily routine disruptions, family dynamics with the sub-theme cultural awareness, and peer interactions. The experiences conveyed by the participants revealed the phenomenon experienced while raising a child with albinism. The findings of this study aligned with the central research question and the three sub-questions.

CHAPTER FIVE: CONCLUSION

Overview

The purpose of this transcendental phenomenological study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. Chapter Five provides an interpretation of the findings from Chapter Four. The implications for policy and practice follow. The chapter concludes with theoretical and methodological implications, limitations and delimitations, and recommendations for future research.

Discussion

This section discusses the study's findings, including the themes developed from transcendental phenomenology thematic data analysis. The findings are supported by empirical and theoretical sources acquired from the study's data. The summary of thematic findings, implications for policy and practice, empirical and theoretical implications, limitations and delimitations, and recommendations for future research are discussed in this section.

Summary of Thematic Findings

The purpose of this study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. Eleven participants shared their lived experiences while raising a CWA. The nine themes that were found from this research study were (a) emotional challenges, (b) parenting adjustments, (c) lack of awareness in society, (d) school experience, (e) self-image, (f) academic success, (g) daily routine disruptions, (h) family dynamics, and (i) peer interactions. The study also revealed four associated subthemes: (a) unknown future, (b) advocating for awareness, (c) teacher interactions, and (d) cultural awareness.

Emotional Challenges

This study found emotional challenges to be a prominent occurrence among participants. The emotional challenges found stemmed from concerns regarding psychological, social, and educational aspects while their CWA attended school. The emotional challenges were found to be directly tied to interactions with society, which made parenting a CWA more stressful and challenging at times than everyday parenting challenges. The paradox of emotions parents face when parenting their children presented itself as sadness, stress, helplessness, devastation, fear, sadness, and disbelief when parenting. After the birth of a CWA, participants experience emotional distress due to their child’s appearance and the healthcare professionals' lack of knowledge of albinism. The emotions were only heightened in times of stress or lack of support available to parents when dealing with OCA. Given the rarity of albinism, participants worry about how society will treat their child(ren) and if they are providing the necessary tools to tackle society's ignorance concerning albinism. A prominent emotional challenge experienced by participants was worry. Participants worried about the unknown future their child would have to endure and what the future would look like. A lack of knowledge of albinism at the time of their child’s birth adds to the emotional fear of the unknown future. A desire for their child(ren) to have a normal upbringing and healthy interactions with peers and society as unaffected siblings or individuals was shared amongst participants. With the constant bombardment of emotions, participants stated difficulties raising a CWA in today’s society. Societies' lack of awareness in the educational setting aided in the emotional challenge participants faced when preparing for their child(ren) to attend school and while attending school.

Parenting Adjustments

When a person becomes a parent, changes are inevitable; however, when the child has OCA, a parent must adjust outside the norm and intentionally plan activities as basic as going to the park or grocery store. As a parent, daily routine adjustments included limiting sun exposure, constant sunscreen application, and navigating the environment to ensure their child’s safety. These changes were integrated into the daily routine of participants. For those with only CWA there were no noted changes needed, given that adjustments were the norm. For participants with unaffected children, the adjustments were not made a big deal and were equated to that of wearing glasses.

Lack of Awareness in Society

Participants reported that it was difficult to interact with society due to the lack of albinism awareness. Participants also reported experiences of isolation and distancing their family from society due to their child’s different appearance or use of assistive devices that attract unwanted attention. Lack of awareness in the educational setting resulted in negative experiences for the participant’s child, which then became a challenge for the participant, as some expressed that their children would keep experiences to themselves and would not express the psychological trauma they were experiencing. In contrast, others noted that their children were open about their experience but chose to self-isolate to avoid bullies because of the lack of support from the administration. The different levels of awareness, either socially, educationally, or personally, impacted the experience participants had in their respective areas. Societal awareness, or lack thereof, affected all aspects of the participant's experience. Lack of awareness in the educational setting resulted in bullying, isolation, and inadequate support. Lack of awareness personally affected participants' interactions with their child(ren) when seeking tools to help CWA. Lack of awareness in society resulted in misconceptions, stares, comments, invasion of privacy, and insensitivity while interacting with society.

School Experience

School challenges CWA experienced also affected the participants. School challenges were identified as school experience including resource availability, teacher interactions, and self-image. The findings showed that positive school experiences were directly related to the amount of awareness and inclusion in the school environment. When experiences were positive, participants noted that their CWA had a positive self-image. When experiences were negative, the lack of resources, inclusion, and awareness gave rise to bullying, issues with self-image, and depression. When a CWA experiences these, the participants also struggle psychologically as they must watch their child experience emotional trauma at the hands of society.

Self-Image

The theme of self-image connects to the parenting challenges participants encounter while caring for children with OCA. Self-image was indicative of the school experience and family upbringing. Participants exclaimed that their self-image was positive once their child(ren) made a core group of friends. Participants described positive self-images based on how they handled albinism within their family dynamics. Some participants noted that their CWA attempted to “fit in” due to social interactions. Self-image issues were noted to be more apparent once participants had children getting ready to go to middle school; at younger ages, self-perspectives are still developing.

Academic Success

Academic success was comprised of the requirement for an IEP with accommodations. An IEP provides the necessary accommodations and support CWA required to access the same general education curriculum as their non-disabled peers. Lack of support from teachers and administration was found to affect academic success negatively. Academic success was found to be related to a teacher’s willingness to advocate for students' needs. A teacher’s ability to understand a student's needs can aid or reduce academic success.

Daily Routine Disruptions

Daily routine disruptions occurred in the CWA routine and were required for academic success or quality of life. The daily routine adjustment noted among all participants was the need for sunscreen. Sunscreen application for participants with younger children requires application by the school nurse and thus missing instructional time. Daily routine adjustments were also noted for quality of life. Many participants noted limiting activities, not participating in certain activities, or avoiding the sun at certain times. The increased risk of skin cancer and light sensitivity noted by participants required participants' CWA to make adjustments. CWA requires support services that require time out of the classroom. CWA also experiences psychological obstacles that require therapy. Participants stated that therapy was provided outside the school, requiring adjustments to accommodate therapy. When provided at the school, the CWA also missed instructional time to attend therapy sessions.

Family Dynamics

In terms of family dynamics, the parent of the CWA deals greatly with the psychological ramifications of OCA. All participants in this study sought to improve the outcome of their child's future, academically, psychologically, and socially. Family challenges were found to encompass family dynamics and peer interactions. The study’s findings show OCA did not affect family dynamics within the immediate family; due to participants operating as a family unit and treating everyone equally. Participants ensured their CWA integrated into society effectively by instilling in them positive affirmations and not letting albinism be a main identifier. Participants made sure their CWA advocated for themselves and were surrounded by peers who accepted and supported them despite their condition.

Peer Interactions

Interaction with peers played a role in the psychological barriers the CWA faced, which also dictated the emotional challenges a participant would endure. Participants noted that their peers accepted and supported CWA when peer interactions were positive. Peer interactions during early years were found to be significant because elementary school occurs during a child's formative years. Participants noted that CWA sought interactions with peers to combat the negative experiences mentioned during some interviews. The acceptance and support from peers helped shape participants' CWA self-image.

Unknown Future

The findings revealed that some of the participants were heartbroken, scared, and devastated upon giving birth to their CWA and getting the diagnosis of albinism. The timing of diagnosis varied among participants. Some participants noted that their child(ren) was diagnosed before leaving the hospital, while others were diagnosed later. Many reported turning to healthcare professionals for answers when participants' CWA was diagnosed. Most participants stated they did not receive much information because the healthcare professionals did not know. Thus, making the moment of discovery a highly stressful experience for the parents. Participants noted that the fear of the unknown future was initially a shock; however, the initial fear subsided as connections were made in the albinism community. The limited resources available to community leaders, school administrators, and families aided in the sub-theme of an unknown future. Participants equated the unknown future to grief, grieving the loss of the future participants had planned for their child(ren) while preparing for their birth. Once participants gave birth, that future was changed, and the prospect of leading a normal life was lost. Participants noted that their hopes of a normal life for their CWA required adjustments to the realization of a different future.

Advocating for Awareness

The participant's accounts of societal interactions gave rise to the sub-theme advocating for awareness. Upon having a CWA, participants worked to improve personal awareness to serve their child(ren) best. Participants noted advocating for awareness in the educational setting, society, and personally. Participants reported working to improve personal awareness by connecting with albinism support groups, such as National Organizational for Albinism and Hyperpigmentation (NOAH). Participants noted that NOAH helped ease emotional struggles by connecting participants with other families for support. Participants also noted that NOAH offered a conference to connect parents and CWA to help with educational accommodations, awareness, and advocacy questions.

Teacher Interactions

Teacher interactions emerged as a sub-theme from the school experience theme. The interactions with teachers served as a contributing factor to the school experience. Participants noted positive experiences when teachers knew student needs, and were welcoming and inclusive. Overall, the interaction with the teachers sets the tone for the school experience given that the teachers and support staff are responsible for providing services to the student and communicating with the parent. Participants noted that teacher interactions were as meaningful as peer interactions, given that the teachers also comprised portions of participants' IEP teams. Teacher's interactions with CWA helped create a positive or negative school experience.

Cultural Awareness

Two of the eleven participants noted cultural awareness within family dynamics. The study’s findings show that cultural awareness, or lack thereof, affected family dynamics for two participants. The inability to understand albinism can affect family dynamics. CWA from families of darker complexion can cause participants to question paternity. The lack of cultural awareness resulted in distance between family members.

Implications for Policy and Practice

This section discusses the implications for practice and policy. I utilized this study's findings for policy and practice implications. The study's findings provided evidence to improve school practices. Implementing the recommendations within this section may assist school administrators and teachers promote a more inclusive school environment for CWAs.

Implications for Policy

Accountability and accreditation are spoken congruently in the United States school system despite being two separate processes. In the United States, K-12 public schools must maintain accountability under the Every Student Succeeds Act (ESSA). Under ESSA, schools are mandated to provide disadvantaged students an equal opportunity, including those who receive special education (Todd-Smith et al., 2024). Every state must undergo an annual evaluation and report card. Accountability evaluations are hinged on indicators such as student achievement, growth, graduation rates, college and career readiness indicators, and school climate (Bae, 2018). States utilize accountability evaluations to generate an education plan that includes academic standards, testing, goals for academic achievement, plans for supporting and improving struggling schools, and report cards (Bae, 2018).

While there are no federal regulations for K-12 public schools to obtain accreditation, requirements for accreditation differ at the state level (Wilkerson, 2017). Roughly twenty states require accreditation (Oldham, 2018). School districts that opt for accreditation are accredited by their state department of education or one of the six regional accreditation agencies recognized by the United States Department of Education (Wilkerson, 2017). The accreditation process includes a periodic review and renewal by an accrediting organization (Wilkerson, 2017).

The school environment is essential to CWAs overall student success. Implementation of an inclusion survey for parents of special needs children can provide an in-depth look at how inclusive school districts are towards CWA and other disabilities. A parent survey geared toward parents of children with special needs may help school administrators identify areas of need and plan implementation strategies that promote a more welcoming and inclusive environment for CWA and other disabilities. School districts can implement policies to ensure accountability of all K thru12 public schools by focusing on continuous improvement and requiring the results of the survey to be reported within the review for re-accreditation. School districts that use information from a regional accreditation process can better impact accountability and support schools, families, and the communities they serve (Elgart, 2017).

Implications for Practice

The findings of the lived experiences of the psychological barriers of parents of CWA in general education classes help to provide implications for the opportunity to promote an inclusive school environment. To address the lack of albinism awareness within the school system, it may also be helpful for school districts and school administrators to establish guidelines that teach tolerance and inclusion, use people-first language where the person is identified before their disability/impairment, such as a person with albinism rather than an albino person, and give presentations on albinism. To address negative psychological barriers of CWAs within the school system, it may also be helpful for school districts and school administrators to establish guidelines that teach assertiveness and coping skills to students with albinism in primary general education classrooms. Assertiveness and coping skills may be incorporated into a teacher curriculum by modeling assertive communication by remaining calm, making eye contact, speaking clearly and confidently to help children develop necessary skills, and role-playing to help children identify ways to handle aggressors, practice different coping strategies, and utilize assertive communication. Coping skills may also be incorporated into small groups or independent learning by showing students how to deal with difficult situations, including taking deep breaths, sitting in a corner reading a book, drawing, playing a game, playing a game, or sharing with a trusted friend.

Many participants in this study experienced the results of the lack of societal awareness and available mental health resources for CWA. The need for more resources and increased societal awareness throughout education is evident. School districts need to implement support systems such as those that promote mindfulness and provide psychosocial skills training and social-emotional learning (Keng et al., 2011). The support systems can be implemented through classroom-based instructions to help normalize and validate feelings and build social skills to assist CWA and those with other disabilities while attending general education classes. School districts may benefit from supporting staff by providing mindfulness training that teaches teachers how to incorporate mindfulness activities into their daily curriculum and dedicating time for students to practice mindfulness and coping skills independently. A support group may provide CWA with the ability to share concerns that they do not feel comfortable sharing with their family or provide strategies on how to have conversations with their parents. The support groups may also provide CWA with different coping skills to improve academic performance and social well-being.

Empirical and Theoretical Implications

The study's findings will be discussed according to the empirical and theoretical implications. This qualitative research study revealed theoretical implications. Goffman's (2009) stigma theory provides the theoretical framework for this study. Empirical implications surfaced through the lived experiences of parents of CWA in general education classes and will be discussed in this section.

Empirical Implications

Empirical implications were evident through the lived experiences of participants in this study. The empirical literature showed the importance of addressing physical and psychological barriers for CWA. Much of the empirical data explored the two major psychological barriers to the educational setting for CWA, myths, and stigmatization. The focus of this study was the lived experiences of psychological barriers for parents of children with albinism in general education classes. There is limited literature specifically addressing the psychological barriers parents of CWA endure as their child attends general education classes. Most literature on CWA addresses the physical barriers CWA face in the general education classroom. This study fills the gap in literature exploring lived experiences of psychological barriers for parents of children with albinism in general education classes.

Psychological Barriers. Psychological barriers play a vital role in the academic success of CWA. Psychological barriers are more damaging than physical barriers due to the trauma that affects many aspects of an individual's life that spans throughout their lifetime (Aborisade, 2022; Brocco, 2016; Chetty & Hargovan, 2021; Dapi et al., 2018; Estrada-Hernandez, 2018; Kiluwa et al., 2022; Kromberg, 2018; Marcon & Maia, 2019; Maunganidze et al., 2022; Reimer-Kirkham et al., 2019). The experiences of parents of CWA attending general education classes are consistent with the empirical literature regarding the affects of psychological barriers on CWA (Marçon & Maia, 2019).

The thematic findings of the lived experiences demonstrated that parents of CWA experience parental challenges that are fueled by their CWA's school challenges and family challenges. Parental challenges consist of emotional struggles, lack of awareness in society, and parenting adjustments. The school challenges encompassed school experience including teacher interactions and self-image. The family challenges consisted of family dynamics and peer interactions. The findings are consistent with the current literature discussing the impact of myths and stigmas on the lives of PWA and their families (Affram et al., 2019; Evance & Penda, 2018; Naiman & Azaliwa, 2021; Reimer-Kirkham et al., 2019; Vernon et al., 2021).

The findings of psychological barriers affecting families of CWA are consistent with current literature. Family members of PWA also face discrimination by the community (Kerr et al., 2020; Marcon & Maia, 2019; Reimer-Kirkham et al., 2019). Mothers face stigmas, distress, and accusations of infidelity from within the family when a child is born into a family of African or mixed descent (Marçon & Maia, 2019).

The lived experiences of psychological barriers affecting families of CWA showed minimal negative impacts on the lived experiences of parents of CWA. The psychological barriers experienced by families of CWA affected the parents emotionally, socially, and their choice of parenting style. Stigmatization of PWA affects all aspects of a person's life; social, family dynamics, and educational attainment. (Affram et al., 2019; Evance & Penda, 2018; Vernon et al., 2021). The participants depicted that the overall lack of albinism awareness affected their CWA psychologically, physically, and culturally. The lack of albinism awareness created psychological, physical, and cultural barriers for the CWA. Thus, psychological barriers for the participants are created as parental challenges. The psychological barriers affecting families of CWA are characterized as paradox emotions, interactions with society, and parenting adjustments. The findings of psychological barriers affecting families of CWA are fueled by the psychological, physical, and cultural barriers CWA face in the general education classroom. The findings are congruent with empirical literature regarding how albinism can break up families; therefore, it is detrimental to explain to parents, more importantly, mothers what albinism is, how to deal with albinism, overcome the negative beliefs and views from family members and the community (Aborisade, 2021; Affram et al., 2019; Brillant, 2015; Brocco, 2016; Chetty & Hargovan, 2021; Kerr et al., 2020; Kromberg, 2018; Mazibuko & Kromberg, 2018; Tambala-Kaliati, 2020).

The psychological barriers of CWA affecting parents, despite negative interactions with society, resulted in an overall positive experience. Outside agencies ' support overcame the emotional struggles, lack of awareness in society, and parenting adjustments within the parental challenges of parents of CWA. Participants in this study also confirmed previous research that shows a need for assertiveness and coping strategies for CWA in general education classrooms (Sofianopoulou et al., 2021). Assertiveness training helps students improve their perception of their experiences and motivates them to deal with stressful situations such as bullying, isolation, name-calling, and discrimination more appropriately (Perry et al., 2018; Veijalainen et al., 2019; Zamani Varkaneh et al., 2022). Children who learn how to effectively navigate their mental health, strengthen their self-management skills, decrease their subjective distress, and improve their social skills with peers are more likely to excel academically (Perry et al., 2018; Veijalainen et al., 2019; Zamani Varkaneh et al., 2022). During her interview, Candice stated, “The staff has been very welcoming when it comes to him. They have started an intervention plan where if he is having different issues, certain teachers at the schoolwork with him individually to keep him calm and walk him through different coping mechanisms to get him back grounded, so he can complete his day."

Theoretical Implications

The theoretical framework for this study was Goffman's (2009) stigma theory, which sought to understand the lived experiences of parents of CWA in general education classrooms. This theory explored three instances where a person can be stigmatized: the stigma of character, physical stigma, and group identity. The participants' experiences demonstrated the issues within the education system that need addressing to assist school administrators in overcoming psychological barriers CWA faces in general education classrooms. This study's findings highlighted areas of concern for academic success contributing to CWA's psychological barriers in the general education classroom. Once an individual is stigmatized, it negatively affects their life, such as educational barriers and low social well-being (Goffman, 2009). PWA are double stigmatized due to their skin color and visual impairment (Goffman, 2009). The principles of Goffman's (2009) stigma theory guided this study in understanding the lived experiences of parents of CWA.

Stigma of Character. The stigma of character, where individuals are stigmatized due to character flaws considered weak, such as low self-esteem, self-worth, depression, or aggression (Goffman, 2009). The social stigmas surrounding albinism are associated with negative consequences such as enacted, felt, and internalized stigmas (Goffman, 2009). The theoretical framework demonstrates that the impact of stigmas associated with albinism is internalized and shapes individual behavior. Internalized stigmas were found to be associated with the themes of self-image, school experience, and teacher interactions. Participants noted that the deviation of a CWAs physical appearance from societal norms gave rise to struggles with self-image for some currently. In contrast, other participants noted that self-image issues will eventually happen as CWA gets older. Internalized stigmas such as depression, lack of self-confidence, and isolation were found to be associated with the school experience and teacher interactions. Participants noted that a negative school experience and lack of support from teachers affected their CWAs ability to build self-confidence and caused episodes of depression and negative self-talk. In contrast, a positive school experience and inclusion from teachers were associated with a positive self-image and increased self-confidence. The themes of self-image, school experience, and teacher interactions align with the stigma of character by depicting how the stigma of albinism affects a CWA mentally.

Physical Stigma. For PWA, the color of their skin depicts imagery that is different from standard expectations (Goffman, 2009). CWAs lack of pigmentation and visual impairment affects them physically in school and are noted in the themes of academic success and daily routine. Participants stated that their CWA required accommodations for academic success. Academic success was found from participant experiences, which involved the need for additional support staff, the use of assistive technology, and sun protection. Participants also indicated that daily routine adjustments affected their CWA physically in school in the form of missed instructional time and alternate outdoor activities. A condition that affects the individual's physical appearance has a lasting impact on a CWAs social development. The stigmatization of CWA has implications for the family, specifically the primary caregiver, psychologically. Participants shared the burden of their child’s albinism emotionally and physically.

Group Identity. Group identity stigmas, where individuals have problems identifying with a particular group, are transmitted through lineages and contaminate all family members (Goffman, 2009). During the study, participants indicated that albinism does not have an affect on group identity. The themes of family dynamics, cultural awareness, and peer interactions supported the theoretical findings. The ability of individuals with OCA to identify with a particular group affects all members of the family. All participants indicated no affect on family dynamics due to the family operating as a cohesive unit. However, a lack of cultural awareness was found among extended family members, which created distance between the CWA immediate family and extended family. Few participants experienced their CWA wanting to distance themselves from family members in a group setting or issues with acceptance from extended family members. Apprehension or lack of acceptance from extended family members of a CWA stemmed from a lack of cultural awareness of albinism. Group identity also relates to the school setting, as CWA seeks acceptance and support. PWA often have a tough time assimilating with society due to the stigmas associated with albinism (Goffman, 2009). Acceptance by one's community is vital for a well-adjusted life. However, in the educational setting, albinism did not affect a CWA's ability to identify with peers. Participants revealed that their CWA are treated the same as everyone else and are accepted and supported by their peers.

CWA can establish a core group of friends in an inclusive environment. Participants also mentioned that a core group of friends increased self-confidence and social interactions.

Limitations and Delimitations

Limitations are potential weaknesses of the study that cannot be controlled (Connelly, 2013). Delimitations are purposeful decisions the researcher makes to limit or define the study's boundaries. This section discusses this study's limitations and delimitations.

Limitations

Limitations of this study include researcher bias, regional diversity, and geographic location. The researcher, the special education teacher with 9.5 years of experience, is the parent of three children with oculocutaneous albinism type two. A journal was kept throughout the data collection process to memo thoughts and feelings. Journaling allowed the researcher to avoid misrepresenting the participants' intended meaning or experience by setting aside personal beliefs and assumptions. The United States comprises four geographic regions, each with its defining cultural characteristics. Participants in this study were from different geographic regions, with one participant located outside the United States. Therefore, one participant's experience in a region may not be the same as in another region due to the cultural differences of different regions.

Delimitations

Delimitations of this study include purposeful sampling, parents of children with OCA, one social media group, and the selection of transcendental phenomenology over hermeneutical phenomenology. Purposeful sampling was used to identify participants who shared certain characteristics. Participants were parents of the more common form of albinism, OCA. Parents of OA were not utilized due to individuals with OA not having any visible deficits outside of their impaired vision. Another delimitation was present in the recruitment of participants. Due to the rarity of albinism, the selection pool is low. Therefore, participants were recruited from one social media group geared toward parents of CWA.

Recommendations for Future Research

The findings of this study contributed to the understanding of the lived experiences of parents of CWA in general education classes in the United States. Throughout the study findings, areas surfaced as recommendations for future research. The first recommendation for future research studies relates to the limitation of OCA. More studies using transcendental phenomenology to understand better the lived experiences of parents of children with ocular albinism. Participants in the study stated their CWA was legally blind and used a cane to navigate different environments, which gained the unwanted attention of society. Research is needed to determine if parents of children with ocular albinism have similar experiences as parents of children with oculocutaneous albinism. Previous literature revealed the issue of psychological barriers causing damaging effects on those with OCA. There is still a gap in the literature on addressing psychological barriers. It may benefit future researchers to conduct a case study that explores the effectiveness of assertiveness training and coping skills in addressing the psychological barriers of CWA.

Conclusion

The purpose of this transcendental phenomenological study is to understand the lived experiences of psychological barriers for parents of children with albinism in general education classes. This study examined the psychological barriers caregivers endured as a CWA access general education classroom. This study focused on the following research questions: What are the lived experiences of parents of children with albinism in school? What affect does albinism have on a person’s character/mentality in school? What affect does albinism have on a person on a student physically in school? What affect does albinism have on a person’s ability to identify with a particular group/race/religion?

Research data collected from the eleven parents of CWA supported each research question. Data collection included individual interviews, a focus group, and a journal prompt. A review of collected data revealed nine themes, including emotional struggles, lack of societal awareness, parenting adjustments, school experience, self-image, academic success, daily routine adjustments, family dynamics, and peer interactions. Four sub-themes were revealed in this study, including unknown future, advocating for awareness, teacher interactions, and cultural awareness. The themes of emotional challenges, lack of societal awareness, and parenting adjustments were found to be parental challenges to explain the lived experiences of parents of CWA. The parental challenges participants experienced were coupled with CWA's school and family challenges. The theory that guided this research study was Goffman’s (2009) stigma theory. The principles of this theory explored three instances where a person can be stigmatized: the stigma of character, physical stigma, and group identity. The lived experiences demonstrated the issues within society to assist school administrators in better understanding the importance of addressing psychological barriers CWA faces in general education classrooms. This study’s findings highlighted areas of concern for academic success contributing to CWAs psychological barriers in the general education classroom. Stigmas are destructive and affect the quality of inclusive education for children with albinism during the formative years of a child’s academic career. Therefore, school administrators must become aware of the findings in this study to ensure policies are implemented that foster an inclusive academic environment that welcomes CWA.

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Appendix A

Liberty University IRB Approval

LIBERTY UNIVERSITY
INSTITUTIONAL REVIEW BOARD

March 20, 2024

Quineesha Phillips
Darren Howland

Re: IRB Exemption - IRB-FY22-23-1759 The lived experiences of parents raising A child with Albinism: A Transcendental Phenomenological Study

Dear Quineesha Phillips, Darren Howland,

The Liberty University Institutional Review Board (IRB) has reviewed your application per the Office for Human Research Protections (OHRP) and Food and Drug Administration (FDA) regulations and finds your study to be exempt from further IRB review. This means you may begin your research with the data-safeguarding methods described in your IRB application, and no further IRB oversight is required.

Your study falls under the following exemption category, which identifies specific situations in which human participants research is exempt from the policy set forth in 45 CFR 46:104(d):

Category 2.(iii). Research that only includes interactions involving educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures, or observation of public behavior (including visual or auditory recording) if at least one of the following criteria is met:
The information obtained is recorded by the investigator in such a manner that the identity of the human subjects can readily be ascertained, directly or through identifiers linked to the subjects, and an IRB conducts a limited IRB review to make the determination required by §46.111(a)(7).

For a PDF of your exemption letter, click on your study number in the My Studies card on your Cayuse dashboard. Next, click the Submissions bar beside the Study Details bar on the Study Details page. Finally, click Initial under Submission Type and choose the Letters tab toward the bottom of the Submission Details page. Your information sheet and final versions of your study documents, **which you must use to conduct your study,** can also be found on the same page under the Attachments tab.

This exemption only applies to your current research application, and any modifications to your protocol must be reported to the Liberty University IRB for verification of continued exemption status. You may report these changes by completing a modification submission through your Cayuse IRB account.

If you have any questions about this exemption or need assistance in determining whether possible modifications to your protocol would change your exemption status, please email us at irb@liberty.edu.

Sincerely,
G. Michele Baker, PhD, CIP
Administrative Chair
Research Ethics Office

Appendix B

Informed Consent

Title of the Project: The lived experiences of parents raising A child with Albinism: A Transcendental Phenomenological Study
Principal Investigator: Quineesha Phillips, Doctoral Candidate, School of Education, Liberty University

Invitation to be Part of a Research Study

You are invited to participate in a research study. To participate, you must be a caregiver of a child with oculocutaneous albinism participant criteria. Taking part in this research project is voluntary.

Please take time to read this entire form and ask questions before deciding whether to take part in this research.

What is the study about, and why is it being done?

The purpose of the study is to understand the lived experiences of caregivers of children with albinism and how psychological barriers affect school and home life.

What will happen if you take part in this study?

If you agree to be in this study, I will ask you to do the following:

1. Participate in recorded virtual individual interviews that will take no more than 1 hour.
2. Participate in a recorded virtual focus group with 10 to 15 other participants that will take one to two hours.
3. Participate in a 500-word or more journal prompt.

How could you or others benefit from this study?

Participants should not expect a direct benefit from participating in this study.
Benefits to society include increasing the information available on the psychological barriers to education children with albinism face.

What risks might you experience from being in this study?

The expected risks from participating in this study are minimal, which means they are equal to the risks you would encounter in everyday life. The risks involved in this study include the possibility of psychological stress from being asked to recall and discuss a prior trauma. To reduce risk, I will monitor participants and discontinue the interview if needed.

How will personal information be protected?

The records of this study will be kept private. Published reports will not include any information that will make it possible to identify a subject. Research records will be stored securely, and only the researcher will have access to the records.

- Participant responses will be kept confidential by replacing names with pseudonyms.
- Interviews will be conducted virtually, where others will not easily overhear the conversation.
- Confidentiality cannot be guaranteed in focus group settings. While discouraged, other focus group members may share what was discussed with people outside the group.
- Data will be stored on a password-locked computer. After three years, all electronic records will be deleted, and all hardcopy records will be shredded.
- Recordings will be stored on a password-locked computer for three years/until participants have reviewed and confirmed the accuracy of the transcripts and then deleted/erased. The researcher will have access to these recordings.

Is study participation voluntary?

Participation in this study is voluntary. Your participation will not affect your current or future relations with Liberty University. If you decide to participate, you are free not to answer any questions or withdraw at any time.

What should you do if you decide to withdraw from the study?

If you withdraw from the study, do not hesitate to contact the researcher at the email address/phone number in the next paragraph. Should you decide to withdraw, data collected from you apart from focus group data will be destroyed immediately and will not be included in this study. Focus group data will not be destroyed, but your contributions to the focus group will not be included in the study if you choose to withdraw.

Whom do you contact if you have questions or concerns about the study?

The researcher conducting this study is Quineesha Phillips. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at qdphillips1@liberty.edu.

Whom do you contact if you have questions about your rights as a research participant?

If you have any questions or concerns regarding this study and want to talk to someone other than the researcher, **you are encouraged** to contact the IRB. Our physical address is Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA, 24515; our phone number is 434-592-5530, and our email address is irb@liberty.edu.

Disclaimer: The Institutional Review Board (IRB) ensures that human subjects' research will be conducted ethically as defined and required by federal regulations. The topics covered, and viewpoints expressed or alluded to by student and faculty researchers are those of the researchers and do not necessarily reflect the official policies or positions of Liberty University.

Your Consent

By signing this document, you are agreeing to be in this study. Make sure you understand what the study is about before you sign. You will be given a copy of this document for your records. The researcher will keep a copy of the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

☐ The researcher has my permission to video-record me as part of my participation in this study.

____
Printed Subject Name

____
Signature & Date.

Appendix C

Individual Interview Questions

Table 1

1. Please tell me your name and more about yourself.
2. Please describe your relationship with a child with albinism.
3. How do you describe your child as a student? CRQ
4. Describe and explain the experiences of school for your child. SQ1
5. Describe the psychological barriers your child experiences. SQ1
6. Describe how physical barriers affect your child in school. SQ2
7. Describe and explain your child’s interactions with their peers. SQ3
8. Explain how school staff, if any, have helped your child to help overcome barriers in the school. SQ2
9. Explain any practical techniques you feel educators need to know to help your child best. SQ2
10. Describe some common misconceptions about albinism. CRQ
11. Describe how albinism affects your daily routine as a parent. CRQ
12. Explain the affects of albinism on your child’s daily routine. SQ2
13. Please describe how the stigma of albinism affects your child mentally. SQ1
14. Describe how your child’s outward appearance affects family dynamics. SQ3
15. Explain and describe how albinism affects your child’s view of themselves. SQ1
16. Explain how you perceive your child is viewed by their peers. SQ3
17. Describe how you perceive society treats your child and family. CRQ

Appendix D

Focus Group Questions

Table 2

1. What are the reasons you decided to participate in this study?
2. Explain in detail your understanding of albinism. CR
3. Explain how you navigate as a parent caring for a child with albinism. CR
4. Explain and describe what you find particularly challenging for you as a parent as your child attends school. CR
5. Explain the process to receive assistance for your child to have an IEP in school. SQ2
6. Explain what it is like having or not having an IEP. SQ3
7. Explain what resources are available to parents of children with albinism. CR
8. Describe what resources the local school district has for mental health. SQ1
9. Describe your experience receiving assistance from other community resources for your child. SQ3
10. Describe your feelings receiving the diagnosis of albinism for your child. CR
11. Describe how having multiple children with albinism affects you. CR
12. Explain what you feel is needed for children with albinism to overcome the psychological barriers in education. SQ1

Appendix E

Journal Prompt

Table 3

1. Please write in 500 words or more, recalling any incidences you have experienced as a caregiver of a child with albinism. Describe your emotional and mental state during the incident.

Appendix F

Participants

Participant Name	Age	Ethnicity	Marital Status	Region	Number of Children with OCA	Child's Age	Type of OCA
Candice	35-40	African American	Single	Midwest	1	5-10	Type 2
Denise	40-45	Caucasian	Married	Northeast	1	10-15	Type 4
Jessica	30-35	Caucasian	Married	Midwest	1	5-10	Type 1
Kate	35-40	Caucasian	Married	Southeast	2	5-10 and 0-3	Type 4
Rachel	35-40	Caucasian	Married	Southeast	1	0-3	Type 1
Rebecca	35-40	Caucasian	Married	West	1	5-10	Type 2
Rhonda	45-50	African American	Single	Southeast	2	15-20 and 20-25	Unknown
Sarah	50-55	Caucasian	Married	Southeast	2	15-20	Type 2 and Type 1A
Sasha	30-35	African American	Married	Southeast	1	10-15	Unknown
Stacy	25-30	African American	Married	Southeast	1	5-10	Unknown
Zuri	30-35	African	Married	Outside the US	1	5-10	Unknown

Appendix G

Themes and Subthemes

Theme	Subtheme
Emotional challenges	
	Unknown Future
Parenting Adjustments	
Lack of Awareness in Society	
	Advocating for Awareness
School Experience	
	Teacher Interactions
Self-Image	
Academic Success	
Daily Routine Adjustments	
Family Dynamics	
	Cultural Awareness
Peer Interactions	

Appendix H

Research Question Responses

Theme	Subtheme	Research Question
Emotional Challenges		Central Research Question
	Unknown Future	Central Research Question
Parenting Adjustments		Central Research Question
Lack of Awareness in Society		Central Research Question
	Advocating for Awareness	Central Research Question
School Experience		Sub Questions 1
	Teacher Interactions	Sub Questions 1
Self-Image		Sub Questions 1
Academic Success		Sub Question 2
Daily Routine Adjustments		Sub Question 2
Family Dynamics		Sub Question 3
	Cultural Awareness	Sub Question 3
Peer Interactions		Sub Question 3