THE EXPERIENCES OF SIBLING DYADS IMPACTED BY ALBINISM IN AFRICA:

AN INTERPRETIVE DESCRIPTION STUDY

by

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Abstract

The bond between siblings is the longest relationship one may have with another individual, but the perspectives and experiences of siblings impacted by albinism have not been fully explored. In parts of Africa, persons with albinism face multiple challenges relating to their vision impairment and sun sensitivity compounded by stigma, discrimination, and safety concerns stemming from deeply rooted spiritual and cultural beliefs and misunderstandings about albinism. Applying an Interpretive Description qualitative design, I explored the experiences of siblings impacted by albinism in five countries in Africa through individual and dyadic interviews with seven dyads. I employed a human rights, family-centred, and disability lens to derive four themes: (1) *Internalizing Processes;* (2) *Normalizing Responses;* (3) *Stigmatizing Experiences;* and (4) *Encompassing Support.* These findings highlight the importance of a strong family system and the need to address the concerns that persons with albinism experience to support them and their family.

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CHAPTER ONE: INTRODUCTION AND BACKGROUND

Through my role as Project Coordinator on a research project on albinism and human rights, I have met many persons with albinism (PWA) who are truly inspiring and appear to live happy lives, despite the well-documented challenges they face in the context of Africa (Reimer-Kirkham et al., 2020; United Nations General Assembly [UNGA] 2019, 2020, 2022a). I have seen them accomplish great things and advocate for other PWA. I wondered whether some of what accounts for the strength, resilience, and even flourishing PWA display might be related to their families of origin and the communities and countries in which they grew up in. More specifically, I was curious about how siblings of PWA (or siblings with albinism) interact with one another and respond to the challenges of living with albinism in Africa, such that there can be well-being and security. This question became the focus of my thesis.

Persons with albinism, particularly in the broad context of Africa, face multiple intersecting challenges due to erroneous misconceptions about the condition that perpetuates them being stigmatized, discriminated, experiencing various degrees of threats to their security, and threats to health and well-being (Reimer-Kirkham et al., 2019; Strobell, 2020; UNGA, 2022a). The cultural and spiritual beliefs and practices associated with albinism have gained international attention in the last decade due to reports of violence including kidnapping, infanticide, murder, and mutilation (UNGA, 2019a). According to Under the Same Sun (UTSS, 2022a) a Christian non-governmental organization (NGO) working in Tanzania and Canada, more than 600 attacks and killings of PWA have been reported in thirty countries, most prominently in countries in Africa. They reported that the actual numbers of attacks are likely to be much higher as many go unreported or undocumented, especially in rural areas. These acts of violence are due to harmful related practices such as using the body parts of PWA in potions or amulets, believing it will bring good luck and fortune (Kaigoma, 2018). PWA have also been believed to be a curse or ghosts and do not die, but rather simply disappear (Imafidon, 2017). Less threatening, but still an impactful belief is that PWA are contagious so people around them would refuse to be close to PWA or touch things that they have handled. PWA also experience derogative name-calling and demeaning remarks due to albinism (Aborisade, 2021).

The beliefs associated with the condition influence the day-to-day experiences of PWA and extend to their families (UNGA, 2021). Substantial research has been dedicated in recent years to exploring the experiences of PWA, especially in areas of health, education, and the societal context (Astle et al., 2023; Ibhawoh et al., 2022; Ikuomola, 2015; Reimer-Kirkham et al., 2020; Taylor et al., 2019). On the one hand, some families feel ashamed or unlucky for having family members with albinism (Lund, 2001), while other scholars have reported the prejudice, stigma, and discrimination toward families (Baker et al., 2010), revealing avoidance or antagonism against family members by the community (Baker et al., 2010; Lund, 2001). Given the reported crimes, families have voiced their constant fear and vigilance because they have a family member with albinism (Bradbury-Jones et al., 2019). As well, some families have been relocated elsewhere and, in some cases, PWA are separated from their families to seek asylum in refugee camps or boarding schools for protection (Nkrumah, 2020; Taylor et al., 2019). Moreover, increased research has been conducted on the experiences of mothers impacted by albinism where they report being blamed, shunned, or abused by their family or community (Likumbo et al., 2021; Reimer-Kirkham et al., 2020). Yet, there is also evidence (some through anecdotal sources such as informal conversations) about the strength and resilience in families that allows PWA to flourish. For example, mothers impacted by albinism have been viewed as human rights defenders for their children because of their perseverance and resilience in raising and protecting them (Ero et al., press; Reimer-Kirkham et al., 2021). This concept of human rights defenders can be likewise applied to other members of the family, such as siblings. In most cases, families grow up with at least one sibling (Mweru, 2017). The bond shared between siblings is usually a long-lasting relationship that can span a lifetime; indeed, a sibling relationship may be the longest relationship one may have with an individual. Siblings typically have the same physical and social environments with experiences that directly or indirectly impact the sibling dynamic and their familiar and communal experiences (Aksoy & Berçin Yildirim, 2008). There is, however, a lack of research focusing on the experiences of siblings impacted by albinism (whether the siblings themselves have albinism or siblings of PWA). Although limited in the literature, accounts of siblings protecting siblings with albinism have been reported (Baker et al., 2010), such that they may as well be explicitly identified as human rights defenders. My research adds to this evidence about siblings as human rights defenders.

Background

To provide the background to this study, in this section, I describe what albinism is and how albinism relates to human rights and disability. I also provide context regarding families in Africa and how having a sibling with a disability, and specifically albinism can impact other siblings. I will also discuss the context of the topic and the scope of this thesis. In addition, I describe my own situatedness and why I have chosen to conduct research on this topic.

Albinism

Albinism occurs worldwide, regardless of gender or racial background (UNGA, 2017). There are two main types of albinism: Ocular albinism (OA), a condition that mainly affects the eyes, and Oculocutaneous albinism (OCA). OCA is an autosomal recessive, inherited condition associated with a complete lack or a significant reduction of melanin biosynthesis in the melanocytes that results in the hypopigmentation of the hair, skin, and eyes (Grønskov et al., 2007; Kromberg, 2018a). Although there are four known types of OCA, Tyrosinase (TYR), OCA 2, Tyrosinase-related protein 1 (TYRP1) Membrane-associated transporter protein (MATP) (Grønskov et al., 2007), OCA 2 is the main focus of this thesis. OCA 2 is the most prevalent type in countries in Africa (Lund, 2001). The prevalence of albinism worldwide is unknown as it varies greatly in geography. Albinism occurs in about one in 18,000 to 20,000 people in the United States of America (National Organization for Albinism and Hypopigmentation [NOAH], 2020) but approximately at least one in 3,900 people in South Africa (Kromberg et al., 2020), and one in 2,673 of the population in Tanzania has the condition (United Republic of Tanzania, 2014).

OCA 2 is a mutation of the OCA 2 gene (formerly known as the P-gene) (Grønskov et al., 2007). The OCA 2 protein is said to be responsible for the normal processing and transport of melanosomal proteins like TYR and TYRP. OCA 2, as well as the other three types of OCA, are recessive disorders, meaning that both parents must be carriers for a child to be born with albinism (Grønskov et al., 2007; Kamaraj & Purohit, 2014). The recurring risk to have a child with albinism with each pregnancy is 25% and siblings without the condition have a 50% chance to be carriers of the gene (Kromberg, 2018b, Making More Health et al., n.d.).

Melanin is the pigmentation that gives colour to the skin and provides protection from the sun's ultraviolet rays. Thus, people with OCA 2 typically have lighter skin and eye colour (Grønskov et al., 2007). Moreover, due to the limited amount of melanin, people with OCA 2 are predisposed to various degrees of skin damage, including actinic cheilitis, actinic keratoses, and skin cancers (Simona, 2004). PWA living in tropical areas have a higher likelihood of skin damage because of the harsh rays of the sun but often are limited in terms of full coverage clothing due to the hot climate (Cruz-Inigo et al., 2011). People with OCA 2, and those with OCA in general, also have varying degrees “of congenital nystagmus, hypopigmentation of iris leading to iris translucency, reduced pigmentation of the retinal pigment epithelium, foveal hypoplasia, reduced visual acuity… sometimes a degree of color vision impairment” and photophobia (Grønskov et al., 2007, p. 2). They often require corrective dark tinted eyeglasses to improve their vision and protect their eyes from bright lights. Therefore, PWA need additional care because of the concerns regarding their eyes and skin. They need to have regular check-ups with eye and skin specialists (i.e., dermatologist, ophthalmologist) to obtain prescription glasses and screening for skin cancer (Cruz-Inigo et al., 2011). They need to apply sunscreen daily, especially when going outside. These health concerns transmit to other areas of life. For instance, some PWA have reported difficulties in school related to not being able to see the blackboard clearly, and the inability to partake in outdoor activities due to being exposed to direct sunlight (Burke, 2019; UNGA, 2020a). PWA have also expressed concerns about finding employment because they cannot work outdoors (Borile, 2019; Duri & Makama, 2018). Furthermore, they have been discriminated against by employers for having albinism and people did not want to touch and buy products from them (Baker et al., 2010; Brocco, 2016). Albinism, in the context of many parts of Africa, impacts the narrative of daily experiences of PWA not only because of their visual disability and sensitivity to the sun, but also due to the cultural and spiritual beliefs relating to the condition.

Human Rights and Albinism

In recent years, awareness of the human rights violations experienced by PWA has reached global attention due to the misunderstandings and myths about the condition (UNGA, 2020b). Their physical appearance makes them “hypervisible”, especially in Africa, which in turn has resulted in human rights issues such as discrimination based on their skin colour (known as colourism) and/or disability and violations to the right to the enjoyment of the highest standard of health, education, employment, and life (United Nations [UN], n.d.a, para. 3). The concerns brought the United Nations Human Rights Council (UN, n.d.b) to adopt without a vote the A/HRC/RES/28/6 resolution to establish the mandate of the Independent Expert on the enjoyment of human rights by persons with albinism to Ikponwosa Ero in April of 2015. The United Nations Human Rights Council also proclaimed June 13th as International Albinism Awareness Day (UNGA, 2014). Since then, key stakeholders across the world have joined forces to respond to this movement. One of the many works of the first UN Independent Expert was collaborating with many African Union mechanisms such as the African Commission on Human and Peoples' Rights, the African Committee of Experts on the Rights and Welfare of the Child, and other international development partners to develop the National Action Plan 2017-2021 to address attacks and other related violations against persons with albinism in Sub-Saharan Africa (UN, 2016). It provides specific and achievable recommendations for plan of actions that would protect the human rights of PWA. It aligns with the UN Sustainable Developmental Goals, "leaving no one behind, starting with the furthest behind first" (UN, 2016, p. 1). Then in June 2019, the Executive Council of the European Union adopted the Plan of Action on Ending Attacks and Discrimination against People with Albinism with a time frame of ten years, from 2021 to 2031 (Africa Albinism Network, n.d.a; African Union, 2019).

Numerous non-government organizations (NGOs) and civil society organizations (CSOs) for PWA, both national and international, have responded to protect and promote the rights of PWA such as access to health, social, and educational resources. For instance, UTSS (2022b) uses different media platforms to educate the public about albinism. They also offer sponsorship through their education program for children, youth, and adults with albinism at all levels of education to provide safe and quality education. Other NGOs include Standing Voice, Albinism Society of South Africa, Tanzania Albinism Society, and the National Organization for Albinism and Hypopigmentation (Strobell, 2020).

The involvement of nurses at Trinity Western University, Canada on the movement on albinism and human rights started with an invitation from the first UN Independent Expert, Ms. Ero to Drs. Reimer-Kirkham and Astle to support the new UN mandate with research, particularly in relation to health and the impact of spiritual/cultural beliefs (Mothering & Albinism, 2022). They formed a research-advocacy-policy network to map the existing albinism research (Reimer-Kirkham et al., 2019) and identify priorities for research (Reimer-Kirkham et al., in review). Based on an international Round table Summit (UNGA, 2019b) and a modified delphi survey (Reimer-Kirkham et al., in review), they initiated a program of research on mothers impacted by albinism, now in its sixth year (for more information: www.motheringandalbinism.com). This research is showing how mothers are impacted by albinism (whether they themselves have albinism or have children with albinism) and often bear the brunt of the stigma, discrimination, and violence from their families and/or communities (Reimer-Kirkham et al., 2020, 2021; Stobell, 2020). Mothers are very much involved in child rearing, and they often protect and advocate for their children such as in areas of health and education. Early in their program of research, it became clear that the lack of studies focusing on the impact of albinism on other members of the family, such as siblings, must also be addressed.

Albinism as a Form of Disability

Contention exists about albinism as a form of disability, with some stating that their poor eyesight is insufficient to classify them in this category (Mswela, 2017; Possi & Possi, 2017).

Previously, disability was viewed exclusively as a medical and physical condition (Hogan, 2019). However, it has now been broadened to consider the impact of social constructs, taking into account the social and environmental experiences of individuals (WHO, 2021). Durojaye and Nabaneh (2019) explain that persons with disabilities can be viewed through a physical/medical or social model. A medical model considers the disability within the person and thus, persons with disabilities have needs that require clinical intervention. In contrast, in a social model, persons with disabilities are viewed to be facing barriers as a result of social structures like political, cultural, social, and economic factors affecting their quality of life (Durojaye & Nabaneh, 2019). Applying these two models of disability, medically, albinism can be viewed as a disability due to their visual impairments and skin sensitivity to the sun, requiring PWA to use visual aids and sunscreen daily (Grønskov et al., 2007; Possi & Possi, 2017). Socially, PWA encounter extraordinary circumstances such as stigma, discrimination, exclusion, and isolation from their community due to deeply rooted cultural and spiritual beliefs that impact their health, safety, and well-being (Brocco, 2015). However, albinism may not often be recognized as a disability with arguments on whether the condition substantially limits major daily life activities and that PWA can control or lessen the severity of the condition and they associated themselves with persons with disabilities because they face similar discrimination (Mswela, 2017). These lines of discussion hinder PWA, including their family, from accessing disability services (UNGA, 2019a). Although eyeglasses or spectacles are known to improve the vision of PWA to correct refractive error (Anderson et al., 2014; NOAH, n.d.a), they do not correct their eyesight because of the low or absence in melanin, which is not curable (Saleem et al., 2019). Thus, even if they wear eyeglasses, depending on the severity of their vision impairment, PWA still need access to accommodations such as using assistive devices at school. Further, the human rights violations experienced by PWA have been reported numerously, including threats to their life, making them such a vulnerable population (UN, n.d.b).

Situating albinism as a form of disability through a human rights model highlights the entitlement of PWA in the necessary services they need for adequate standard of living. PWA can be "seen as subjects of human rights and are therefore entitled to non-discrimination and inclusion in all aspects of society" (Astle et al., 2023, p. 2). This means that PWA can draw from several instruments that address concerns of persons with disabilities including the Convention of the Rights of Persons with Disabilities (UN, 2006) and the African Charter on Human and Peoples' Rights on the Rights of Persons with Disabilities (African Union, 2018). According to Brocco (2015), viewing PWA as persons with disabilities allows for "alternative and more suitable epistemologies for albinism" (p. 1153) and provides PWA with an explanation to their community as to why they cannot perform certain things that abled bodies could (like participating in agricultural work).

Siblings Impacted by Disabilities

Siblings have a unique and special relationship that starts from birth (Aksoy & Yildirim, 2008). This relationship is built on shared experiences and family values, with siblings often providing each other with social and emotional support. Siblings, as part of a family, play an extremely significant role in one's identity (Dew et al., 2008). However, when one sibling has a disability and is treated unfavourably by the people they interact with, the support may extend beyond what is typically expected of a sibling relationship (Dew et al., 2008). Having a family member with a disability impacts the structure and functionality of the family, whether positively or negatively, as well as the relationship they have with each other and the role they play within the family (Aksoy & Bercin Yildirm, 2008). The siblings without a disability have distinctive experiences throughout their lives that can include conflicting feelings about their sibling's disability and complex family dynamics (Meltzer, 2021). They may also need to navigate around the disability systems and adjust to having caring responsibilities such as being advocates for their sibling with a disability (Rossetti et al., 2018).

Siblings and Albinism

There has been little discussion in the academic literature about siblings affected by albinism. Where their experiences are addressed, siblings with albinism have been reported to receive more attention from parents than their siblings without albinism (United Nations Children's Fund [UNICEF], 2017). Lund (2001), for example, reported that PWA were offered extra help or protection by their siblings such as ensuring that they do not spend too much time out in the sun. However, in some cases, siblings are reported to have negative attitudes toward their sibling with albinism. Siblings may express jealousy, worry, or resentment toward the affected child for gaining more attention from their parents (Kromberg, 2018b). Participants from Aborisade's (2021) study stated that they experienced prejudice and physical violence from their family members, including their siblings, for having a disability and specifically for having albinism. A few articles have emphasized the importance of acceptance of albinism by the family to enhance the welfare and security of PWA (Baker et al., 2010; Brocco, 2015; 2016). Siblings have an important role in the family for the support and love they provide to one another. When there is more than one sibling with albinism, the siblings can form tight and unique relationships due to shared experiences and understandings. A family, currently holding the Guinness World Records for the most siblings with albinism, shared on social media their experience of stigma and discrimination during their childhood years (Pilastro, 2021). Amid the challenges they encountered, they supported one another, especially in school, and worked toward educating their community about the condition.

In the context of healthcare, a family-centred framework or approach is often utilized, as it acknowledges that the experiences of one family member impact the whole family, which includes the siblings (Barr & McLeod, 2010). This framework considers the whole family as their patient/client and therefore broadens the responsibility of healthcare providers to address the concerns of the patient, parents, and siblings and involve them in decision making (Barr & McLeod, 2010). Meltzer (2021) emphasizes the model of sibling support, which is a support model to promote outcomes for siblings of persons with disabilities. Sibling support focuses on three central principles: (1) recognize siblings as part of the family system, (2) amplify siblings' voices (address their own rights and not as an addition to parental support), and (3) respond and build to siblings' shared identity and experiences. The principles acknowledge the need to provide specific interventions/evaluations for siblings as a distinct field in practice. By understanding the experiences of siblings impacted by albinism, healthcare providers can gain insights into the growth and development of PWA, how the relationship between siblings develop over time, and identify ways to provide effective support for siblings impacted by the condition.

Family in the Context of Africa

In many countries in Africa, family structures are categorized into two ways: the nuclear family (which includes father, mother, and children), and the extended family (comprising of other relatives like grandparents, cousins, aunts, and uncles) (Alabi & Olonade, 2022). It is common for the extended family to be involved in raising the children (Mokgatle-Nthabu & Lewis, 2007). Thus, it may be that when one speaks of the family, one is not just referring to the nuclear family, but rather the extended family (Amos, 2013). Mokgatle-Nthabu and Lewis (2007) explain that families are communities, and everyone has biological, social, marital, and/or neighbourhood ties with one another. Families become influenced by the needs and values within the family and the structure of the community. Marriages are widely seen as a crucial aspect of a family and the roles include the mother being the homemaker, the father as the breadwinner, and the children who are dependents on the parents (Mokgatle-Nthabu & Lewis, 2007). In recent years, African scholars, as elsewhere, have acknowledged the changes in social structures of families and how the social relations have become more complex and dynamic (Alabi & Olonade, 2022; Sooryamoorthy & Makhoba, 2016). For example, many individuals have started to delay or reject entering marriage to pursue a career. Women, especially, now have greater opportunities to pursue education or economic possibilities. Even when women get married, they continue to be in the labour market to support the household (Sooryamoorthy & Makhoba, 2016). Given such variations in family structures and the evolving nature of families, one must contextualize to the unique characteristics of individuals and within a community when examining what constitutes a family.

My Situatedness

Recognizing that I have a personal connection with the topic of interest, I am sharing my experience as a person with albinism. I emigrated from the Philippines to Canada during my teenage years. I experienced my elementary and high school years with a sibling, Thomas, who himself has albinism. We were the only two students in school with albinism while residing in the Philippines. Our blond hair and pale complexion made us stand out among our classmates. In many ways, being siblings with albinism strengthened our relationship because we understood the challenges we faced daily, especially in school when we were unable to see the blackboard or were unable to attend outdoor activities for long periods of time. We defended one another when people stared at us or called us names. We advocated for one another, letting each other's classmates and teachers know what albinism was and why we needed to sit in the front row of the classroom. Thomas and I would put on sunscreen together before going outside. We would remind each other to wear a hat before leaving the house. He and I shared eye appointments, and we supported each other when we had our eyes surgically operated. We were each other's support system, companion, and protector, especially in school where our parents could not often be around. Now that my brother and I are grown adults and have a younger brother, Robin (currently eight years old) who also has albinism, we are both quite committed in ensuring that our youngest sibling has access to whatever he requires and in encouraging him to achieve whatever he sets his heart and mind to. Although his fair appearance is not as distinct here in Canada as ours was in the Philippines, we nonetheless respond to his condition and support him. For instance, Thomas and I regularly attend meetings with Robin's Vision Advisor and teachers in school to explain our vision and skin concerns, and how it impacts Robin's school activities. Reflecting on how involved my siblings and I are in our shared daily experiences, I have developed an interest in understanding sibling relationships in the context of albinism.

In addition, I came from a humble family in a small province in the Philippines where opportunities were slim. My family, however, showed love through acts of giving and they strived for a better life that eventually brought my family here in Canada. I am the product of a multi-generation's hard work, perseverance, and countless sacrifices, specifically by my parents and grandparents. My family is the main reason I am leading a life where I am able to thrive. Thus, I appreciate just how important one's family is. Although this thesis is centred around siblings, I could not ignore nor should I ignore just how important each member of the family is, including parents, the extended family, and other individuals whom one would consider as part of their family.

I am currently the Project Coordinator for the *Mothering and Albinism* research project. I started as a research assistant during my undergraduate degree in nursing, assisting on a mixed-method study on the intersection between albinism, human rights, and cultural and spiritual beliefs (Reimer-Kirkham et al., in review). My participation in this project heightened my interest in albinism and on the field of academic nursing research. During my time studying my master’s degree, I was given the opportunity to be involved in a qualitative study on exploring the experiences of mothers impacted by albinism (mothers with albinism and mothers with children with albinism). Reflecting on the conversations I had, some mothers disclosed that siblings are indeed impacted by albinism. I heard that siblings would have greater responsibilities such as washing the dishes because the sibling with albinism has sensitive skin. I also heard of siblings reminding their brother/sister with albinism to put on sunscreen or to wear their hat. I then wondered how else their day-to-day experiences are affected because of albinism but I have found very limited information in the current literature.

With the heightened health and safety concerns of PWA in countries in Africa (UN, n.d.a), I am focusing my thesis on this continent. Despite my interactions with many individuals living in different countries in Africa during my time as a research assistant and now as a Project Coordinator, I disclose that I am very limited in my understanding of the African context. I spent half my life in the Philippines and the other in Canada. I have never been to any of the countries in Africa, nor was I able to travel for this thesis due to the COVID-19 pandemic restrictions. I have read ample news reports and academic articles about the continent, but as a woman with albinism now living in the Global North, I recognize that I may never fully understand what it is like to have the condition as someone of African heritage. Thus, my personal aim for this study was to learn from those who have the experience and amplify their voices so that their stories could finally be heard. That being said, I recognize that I am further privileged. I am a woman with albinism now living in Canada and I am most often mistaken as a “white woman.” I am seen as what society may describe as having “normal” colour because of my pale skin, shifting my circumstances as the perception of colourism in the western world puts me at an advantage. For PWA in Africa, this perception is not the case as they are often seen as an outsider for having white skin (Brocco, 2016) and those with darker complexion are recognized as “melanin privileged.”

Furthermore, as a nurse working in community settings, I recognize the various roles families may undertake in the management of health conditions. Even when the clients have grown, it amazes me how siblings would step up to support their sibling with a disability or other health conditions. They would even take over the responsibilities of caring for their siblings when their parents can no longer do so (Rossetti et al., 2018). However, sibling perspective and support can be under-recognized and unaddressed, with family support often focused on the parents (Meltzer, 2021). My interest in addressing this topic is not only to acknowledge the endless support and sacrifices siblings give to one another but to also address the gaps in healthcare to better provide siblings with support.

Definition of Terms

To ensure clarity throughout this study, this section explains the definitions of the main terms that will be used.

Albinism

In this study, albinism refers to Oculocutaneous Albinism Type 2 (OCA 2), an autosomal recessive, inherited disorder where there is a reduction of melanin or complete lack of biosynthesis in the melanocytes, resulting in the hypopigmentation of the hair, skin, and eyes (Kromberg, 2018a; Grønskov et al., 2007). They have varying degrees of visual impairment and are at an increased risk of skin cancer. In addition to the physical health concerns, PWA, especially in countries in Africa, experience human rights violations (ranging from stigma and discrimination to attacks, murder, and mutilations) due to spiritual and cultural beliefs associated with the condition (Reimer-Kirkham et al., 2019). The fear caused by these atrocities greatly impacts the psychosocial health of PWA (UNGA, 2017).

Family

For the purpose of this thesis, family is defined as “a group of persons united by the ties of marriage, blood, or adoption, constituting a single household and interacting with each other in their respective social positions, usually those of spouses, parents, children, and siblings” (Bernard, 2022, para. 1). Family may include extended family members such as grandparents and other relatives (Alabi & Olonade, 2022), a conceptualization that is particularly applicable in the African context. I recognize, however, that there are various individuals who one may consider as part of their family. Given the recent changes in family and social structures, this study opens this definition to whoever individuals consider their family. I also explored family dynamics, which are the “patterns of interactions among [family members], their roles and relationships, and the various factors that shape their interactions" (Jabbari & Rouster, 2021, para. 1). Studying the family includes the cultures, values, beliefs, and practices of and about the families in their societal context as well as the inclusion of the ways families are connected to each other and to other societal institutions (White et al., 2015). This study acknowledges the call of the UN (2019) to protect the "individual rights of all family members" (p. 1).

Disability

According to the World Health Organization (WHO, 2021), disability refers to an individual's interaction with a health condition (in this case, albinism) and personal and environmental factors (such as attitudes and behaviours presented by communities, access to hospitals or clinics, and family and social supports). This study acknowledges that PWA fall under the category of persons with disabilities not only due to their visual impairment and sensitivity to the sun but also because of the extraordinary circumstances they face on the account of stigma, discrimination, and violence (UNGA, 2020a).

Health

Health in this study refers to the "state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The enjoyment of the highest attainable standard of health is one of the fundamental rights of every human being without distinction of race, religion, political belief, economic or social condition" (WHO, n.d.a, para. 1). This definition presumes that an individual is not wholly healthy unless they have complete well-being.

Human Rights

As defined by the UN (1948), human rights are rights that all human beings are entitled to regardless of age, race, gender, nationality, ethnicity, language religion, or other status. An individual’s human rights include the rights to life, liberty, and security. Everyone is entitled to their human rights, without discrimination, as outlined in the Universal Declaration of Human Rights (UN, 1948).

Human Rights Defender

Human rights defender is a term used to describe individuals who can “act to address any human right (or rights) on behalf of individuals or groups” in a peaceful manner (United Nations Human Rights Office of the High Commissioner [OHCHR], n.d.a, para. 2). There is no specific definition of who can be a human rights defender. The UN, however, refers to “individuals, groups and associations… contributing to… the effective elimination of all violations of human rights and fundamental freedoms of peoples and individuals” (UNGA, 1999, p. 2). They seek to promote and protect the civil and political rights as well as the realization of people’s economic, social, and cultural rights. They may be active in any part of the world.

Sibling

By definition, a sibling is one of two or more individuals who have common parents (Marriam-Webster, n.d.). A sibling, in this study’s context, extends to half-siblings where two or more individuals share one parent (Urban Dictionary, n.d.) as well as stepsiblings or siblings not biologically related but connected by marriage (Cambridge Dictionary, n.d.).

Social Determinants of Health

Social Determinants of Health (SDoH) is defined by the WHO (n.d.b) as the “non-medical factors that influence outcomes” (p. 1). These forces encompass social norms, political structures, and economic policies and opportunities. Examples of SDOH include, but are not limited to, early childhood development, education, income, social support system, housing, employment, culture, and access to healthcare services.

Purpose and Objectives

The purpose of this study was to explore the experiences of siblings impacted by albinism in the African context. The objectives were:

1. To examine the family dynamics of having a sibling with albinism, including their social, political, economic, and historical contexts,
2. To analyse strengths and challenges between siblings (intra-family) and in the community (extra-family) in relation to albinism, and
3. To explore implications for healthcare providers to enhance a family-centred approach that integrates sibling support as part of the healthcare for families affected by albinism.

Research Design

This study utilized a qualitative approach with Interpretive Description as the methodology (Thorne, 2016) and integrated dyadic interviewing and analysis (Caldwell, 2014; Collaço et al., 2021). I recruited participants through convenient and snowballing sampling methods. Virtual data collection occurred in a ten-week period during the months of October, November, and December of 2022. I interviewed a total of fourteen participants: seven pairs of siblings (PWA and siblings of PWA) from different families in five countries (Ghana, Nigeria, South Africa, Tanzania, and Zambia). Data collection occurred through individual and dyad interviews with each pair of siblings, keeping a reflexive journal as fieldnotes, and debrief conversations with my Committee. All interviews were audio-recorded and transcribed. For data analysis, I used an adopted version of the Framework Method (Collaço et al., 2021) that I further modified for a deeper understanding and integration of the dyadic dynamic. I created a matrix to identify common themes and patterns and then imported it to NVivo™. As a person with albinism with my own set of siblings, I maintained an awareness of my situatedness throughout my research process. Through the process of reflexivity, I recognized that, although I come from the diaspora (Philippines), my perceptions, culture, family structures, and values vary greatly from my participants. Residing now in Canada, often mistaken as a “white woman,” I acknowledge that this further puts me at place of privilege.

Outline of my Thesis

This thesis is organized into six chapters. In Chapter One, I provided the background to albinism and the relevance in the need to explore how albinism impacts siblings. Chapter Two explains the process of conducting a literature review and presents the findings of the current literature about siblings impacted by albinism. In Chapter Three, I describe this study’s methodology with the focus on conducting a qualitative dyadic study as well as the process of recruitment, data collection, and data analysis. I then describe the participant sample and findings in Chapter Four, followed by a discussion of the interpretation of the findings in Chapter Five. Finally, Chapter Six provides recommendations for non-governmental and civil society organizations, policy and government, health and social services, nursing, and research on how best to support siblings impacted by albinism and the family, through the lens of disability, family theory, social determinants of health, and human rights.

CHAPTER TWO: LITERATURE REVIEW

Conducting a literature review entails summarizing and evaluating the body of writings about what is already known of a specific topic (Knopf, 2006). For students, and researchers in general, a literature review provides an overview of a body of research that one is unfamiliar with (Jesson et al., 2011). It eventually provides the researchers the ability to identify knowledge gaps in existing knowledge. I conducted a literature review to gain an understanding of existing data about siblings impacted by albinism. In this chapter, I will describe the search strategies used, including the search strings, databases, and inclusion/exclusion criteria. A description of the included articles will also be discussed leading to the analysis of findings in the extant literature.

Search Strategies

With the assistance of a research librarian, Elizabeth Kreiter, I created a search strategy for the following databases: Academic Search Complete, Academic Search Complete Subject Headings, CINAHL, CINAHL Subject Headings, MEDLINE, Sociological Abstracts, PsycInfo, and PsycInfo Thesaurus (see Appendix A for the Literature Review Search Strategy). Based on the research objectives of the study, relevant terms and keywords were used using the Boolean AND or OR strings. On the first attempt, the following search strings were used: Albinism OR albino*; sibling* OR brother* OR sister*. However, it yielded very few results. The second attempt included keywords relating to disability and family: Albinism OR albino* OR disabilit*; sibling* OR brother* OR sister* OR famil* OR kin*. The combination of these keyword terms generated tens of thousands of results. Scanning the first five pages, most articles were irrelevant, which meant that the search strings were too broad with the addition of the term disability. On the third and final attempt, the keyword disability was removed: Albinism OR albino*; sibling* OR brother* OR sister* OR famil* OR kin*. This provided more applicable and relevant results. Through the iterative process of running searches, only two facets (i.e., albinism and siblings) were used for the final search, although the second facet was broadened somewhat to include family and kinship. The final search was conducted in September 2022 (no limiters were placed on the search).

All the articles were exported from the databases and uploaded as RIS files into Endnote, a software that stores and manages references and citations (Clarivate, n.d.). Removing 304 duplicates, a total of 3,290 articles were included in the initial screening.

Searching for articles also involved using Advanced Google Search and Google Scholar, which has been used for secondary syntheses (like meta-analysis and literature reviews). The search was broadened to grey literature for a more comprehensive review of all the materials available about a topic and to prevent publication biases or selective outcome reporting (Baguss, 2019). Due to the great number of results, only the first five pages were screened. Similar search terms were used. Forward and backward searches were also conducted from relevant articles.

I then screened all the articles for eligibility. Academic articles were included if they met the following criteria: Peer-reviewed; English and French language; substantive discussion of siblings' experience (minimum of 100 words). Masters and Ph.D. theses or dissertations were included if they met these inclusion criteria. Articles with a clinical, biological, or medical focus were also included due to the sparse data on the topic of interest. These articles are considered "somewhat related" to the topic because it considers how biological (including genetics) and environmental factors impact the health concerns of siblings impacted by albinism. Articles that were excluded were those that are not peer-reviewed; not in the specified language; had limited discussion of siblings' experience; and bachelor's level theses. For grey literature, sources were included if they were reports or studies from NGOs, CSOs, or government with substantive discussion on siblings and albinism (minimum of 100 words). All in all, Javangwe and Mukondyo's (2012) article was the only article that addressed siblings (children) impacted by albinism as the primary focus but reported about the comparisons of their play behaviours. Aborisade (2021) had substantive information about sibling and albinism experiences, but the overall article was broader to explore experiences within the family.

After completing the selection process, I used the Matrix Method to conduct a literature review (Garrard, 2017; see Appendix B for an example of the literature review matrix). All the articles were then uploaded into NVivo™, a software that stores and manages data (Lumivero, n.d.). The articles were read, and a coding method was used to organize the data into categories of themes and patterns (Polit & Beck, 2020).

Information about the Studies

A total of 32 articles were included in this literature review (see Appendix C for PRISMA). Research methods are as follows: ten qualitative, three quantitative, one mixed, one synthesis, fourteen case studies, and three discussion articles. The authors represented health science (psychology, medicine, dermatology, and ophthalmology), art and humanities (critical arts and philosophy), and law. The earliest article was published in 1946 and the most recent in 2021, with fifteen articles published in the last 10 years. Sixteen articles had an African context (South Africa, Malawi, Zimbabwe, Tanzania) and seven were conducted in Asia (Turkey, Oman, Taiwan, Japan). Of the sixteen articles written with an African context, only seven articles had a lead author from an African country.

Synthesis of the Literature Review

I derived three main themes from my analysis of the literature: (1) clinical reports of siblings with albinism, (2) family experience between siblings impacted by albinism, and the impact of the perspectives and behaviours of their parents, (3) and their shared experiences in a community context.

Clinical Reports on Siblings with Albinism

Twelve articles presented case reports on siblings with albinism. The focus of the articles was to describe clinical findings regarding skin and vision and, interestingly, psychological disorders and behavioural patterns among siblings with albinism.

Skin and Vision

Cases about skin and vision were presented by a few authors. For example, Baskurt et al. (2011) discussed the presence of basal cell carcinoma (BCC) between two brothers with albinism. The brothers engaged in farming and were both found to have lesions on their trunk area. They reported that the occurrence of BCC between the brothers demonstrated that environmental factors, such as being outside and exposed to ultraviolet radiation, as well as genetic factors contributed to the development of nonmelanoma skin malignancy. They, therefore, emphasized the predisposition of skin diseases like BCC with PWA. Ellis and colleagues (1995), on the other hand, presented a case between two sisters with OCA, and both presented with bruising tendencies. Blood work on the sisters revealed that they had a storage pool defect in their platelets, leading to a diagnosis of Hermansky-Pudlak syndrome (HPS). Ellis et al. (1995) stated that identical platelet defect has not been described to be associated with albinism but “may be that an analogous protein deficiency in the melanosome membrane could account for the tyrosinase-positive albino phenotype where melanogenesis itself is normal” (p.

294). They concluded that the prevention of skin disease and vision and hematological management involves an awareness of the diagnosis of the disease.

Further, Heinmiller et al. (2016) conducted a study that discussed concerns regarding the vision of siblings with albinism. They presented on the concordance of vision and structural features between siblings with albinism with 111 patients from 54 families. The purpose of the study was to determine whether the visual function of PWA can be predicted based on the performance of a similarly affected biological sibling. The results revealed that the iris grading, foveal grading, and presence or absence of macular melanin had minimal variations between siblings with albinism. But they found that the markers of visual function were varied and there was a wide range in best-corrected visual acuity and the presence or absence of stereoacuity. They suggested that counseling parents about the vision of their children with albinism is important and that the visual function may be different between affected siblings.

Psychological Disorders and Albinism

Psychological disorders of PWA were of interest in the literature. Clarke and Buckley (1989) stated that there have been discussions about psychiatric conditions being associated with albinism. They presented a case report on two siblings with albinism (a brother and a sister), both having psychotic disorders “indistinguishable from schizophrenia” (p. 551). The brother had the physical features of tyrosinase-negative OCA, with no pigmentation to the hair, skin, and eyes. He was reported to have depression, insomnia, inferiority complex and an overdose episode with imipramine. He had auditory hallucinations and was diagnosed with schizophrenia. He was admitted to the hospital after threatening to kill his father. He was presenting with religious delusions and his condition was resistant to neuroleptic drugs. However, he was discharged nine months after treatment. He remained unemployed and lived with his parents since his illness began. The sister had a similar schizophrenic disorder and was treated with neuroleptic drugs for a brief period but then she refused treatment for 12 years. Clarke and Buckley (1989) referenced Baron (1976) who had a similar case report. They concluded that familial association exists between albinism and schizophrenia, hypothesizing that this may either be due to genetic linkage, or a metabolic abnormality associated with albinism that predisposes them to schizophrenia.

Other disorders have been discussed that were associated with albinism such as Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Disorder (ASD). Ünsel Bolat (2020) discussed a case report on two brothers with OCA. An 11-year-old boy with albinism was described to have poor social skills, displayed aggression in social situations, and showed limited eye contact. Using the Childhood Autism Rating Scale, his score indicated that he had ASD. His older brother at 13 years of age presented with symptoms of inattention and hyperactivity. Through the ADHD Rating Scale and the Child Behavior Checklist, his scores revealed that he had ADHD. Both brothers were then recommended for treatment for their respective diagnoses. Similar to the studies above, Ünsel Bolat (2020) stated that diagnosis is crucial as there is an increase in the prevalence of PWA having psychological disorders such as ADHD and ASD.

In addition to psychological disorders, the intellectual development of PWA and their siblings without albinism has been studied. Beckham (1946) observed his participants for 10 years and found that children with albinism had similar intellectual development to that of their siblings who do not have albinism. Behaviours of siblings with albinism and siblings without albinism were even compared through interactive play by Javangwe and Mukondyo (2011). Through observation and the completion of a behaviour checklist, their results showed that children without albinism displayed more pro-social behaviours than children with albinism, however, aggressive and affiliative play behaviours were the same.

Family Experiences

Most evident in the literature is that PWA often feel different from their siblings because they have albinism (Aborisande, 2021; Blackenberg, 2000; Huang et al., 2022; Olagunju, 2019). They compare their physical appearances to that of their siblings without albinism. Combined with the circulating beliefs and practices associated with it, self-perception of their experiences with their siblings is greatly impacted (Blackenberg, 2000). The experiences between PWA and their siblings vary in the literature with positive and negative experiences not only concerning siblings but also in relation to the views and behaviours of their parents.

Siblings' Positive Interactions

Multiple studies recounted positive experiences of PWA and their siblings (Baker et al., 2021; Estrada-Hernández & Harper, 2007; Ezeilo, 1989; Lund et al., 2015). These articles focused on the health and security situations of PWA and the authors provided brief mentions of siblings' experiences. Lund (2001), who conducted research on 138 children with albinism in Zimbabwe, shared that the experiences between siblings were largely positive. One participant said that he was treated like an "ordinary guy" (p.3) and his siblings had sympathy for what he goes through. Some PWA even experienced overprotection from their siblings (Huang et al., 2022). One individual without the condition stated that her sibling with albinism was spoiled, protected, and well cared for by her sisters (Blackenberg, 2000).

Caregiver Role

Another theme noticed in the literature is the caregiver or supportive roles that siblings play for the other who has albinism. For example, there were siblings who offered help, ensuring that their sibling with albinism did not spend large amounts of time under the sun to do chores or prepare food (Lund, 2001; Kromberg, 2018a). Some siblings also offered emotional support, especially when the sibling with albinism felt apprehension or anxiety in their community (Ezeilo, 1989). However, this caregiver role can be seen as a responsibility placed upon the sibling who does not have albinism. Due to the threats to safety and security, for example, siblings may be expected to accompany the other who has albinism such as going to and from school (Lund et al., 2015). The stigma and discrimination by association as well as the impact of caregiver burden may cause the family, including their siblings to be less willing to help or even avoid their family member who has albinism (Affram et al., 2019).

Siblings' Negative Interactions

Persons with albinism may also experience negative attitudes and behaviours from their siblings. Siblings may not accept the noticeable difference of their siblings with albinism (Blackenberg, 2000). Blackenberg (2000) interviewed Benito Dacosta Mwanza, a person with albinism in South Africa who shared his experience with his family. He was hurt because his sisters insulted him. He shared that having a mixed family that included siblings with and without albinism impacted him so greatly that he vowed to avoid having a mixed family to prevent sibling rejection. In addition, Aborisande (2021) conducted a qualitative study on family childhood experiences of PWA in Nigeria. Many participants reported prejudice and even violence against them by their siblings. One participant shared that he was not treated as a human by his family and siblings; they ridiculed him and laughed at him because of his disability. Physical violence was reported by participants where the occurrences were too many to recount. One participant stated that the maltreatment done by his parents and older siblings was because of his albinism status. He reported that when he was beaten, they often mentioned that their resentment of him was due to his albinism condition. In more severe cases, siblings may be involved in the attacks against PWA. A report by Amnesty International (2016) included a case where a woman with albinism was lured by her brother and then killed and mutilated by three men.

Influence of Parents

The negative perceptions of their siblings were attributed to the increased or special attention provided by their parents (Lund et al., 2015). PWA require the daily use of sunscreen and long-sleeved clothing to ensure skin protection (Grønskov et al., 2007). They also need to see skin and vision specialists for regular checkups. But siblings without albinism, especially when they are children, may not understand why their sibling with albinism needs this additional attention from their parents (Lund et al., 2015). Thus, siblings may be resentful or jealous of the other who has albinism (Blackenberg, 2000; Kromberg, 2018). Blackenberg (2000) explained that the apartheid era may have influenced the perception that whiteness leads to better treatment, accompanied by the actual protective care provided to a person with albinism.

In contrast, parents may also be the ones who resent or do not support their children with albinism. For example, some children with albinism were unenrolled from school to avoid public appearances or for their siblings to be able to continue with their education (Aborisande, 2021; Olagunju, 2019). The stigma, prejudice, and violence against PWA from their families were often not only by their siblings but from their parents and relatives (Aborisande, 2021; Blackenberg, 2000). They may be avoided, called derogatory names, or beaten by their parents (Aborisande, 2021).

Some scholars suggested that families, including their siblings, must be provided with genetic information about the condition (Aborisande, 2021; UNICEF, 2011). A scientific understanding of albinism would help them understand how albinism occurs and the medical support needed for their family with albinism. Siblings are genetically impacted as their parents are carriers of the condition and thus each sibling born has a 25% risk of having albinism (Kim, 1999). Furthermore, siblings without albinism are at risk of being carriers of the condition which could affect their future when they decide to have their own children (Kromberg, 2018b).

Community Experiences

Families, including their siblings, may also be affected by the beliefs and practices about albinism by association. Some families with albinism were reported to be viewed with suspicion and treated differently by their community (Lund et al., 2015). Nomasonto Mazibuko, a PWA, worked as an educator in a school in South Africa for two decades with her sister who was the school principal at that time (Mazibuko & Kromberg, 2018). Mazibuko was initially accepted for the position of deputy principal but then rejected and discriminated against because of her albinism. She was then fired along with her sister who was accused of nepotism.

Moreover, a family’s safety was also reported to be threatened because they share the same home. A family interviewed by Lund et al. (2015) reported that some members in their neighbourhood would point out their house to strangers, saying that they have a family member with albinism. In some cases, families had to relocate for the protection of their family members with albinism (International Federation of Red Cross and Red Crescent Societies, 2009). It is life-altering not only for PWA but also for their families, as they left their livelihood and must always be vigilant of their surroundings. Due to the threats to safety and security, many children with albinism were even removed from their families and placed in shelters or special schools (Cruz-Irigo et al., 2011). It can be very difficult for siblings to be separated from each other, not to mention frightening to hear of the reported attacks and know that their siblings could be in danger. The literature provides evidence of such grieving cases where PWA were attacked in their own homes. International Federation of Red Cross and Red Crescent Societies (2009) reported a horrific incident where a woman with albinism was killed by a group of men in front of her sisters and mother. These events are surely traumatizing to the siblings and the family.

Discussion

Given the genetic influence of the condition and how it may present between siblings, understandably, research has been conducted to discuss case reports relating to skin and vision of siblings with albinism (Baskurt et al., 2011; Ellis et al., 1995). Less apparent is the rationale for the exploration of psychological disorders and their correlation with albinism (Clarke & Buckley, 1989; Ünsel Bolat, 2020)); the question arises of whether the underlying assumption relates to seeking a genetic or physiological correlation, rather than causation stemming from psychological, social conditions of discrimination and stigma. Along with the literature reviewed on genetic cases and psychological disorders, my main focus was on family experiences. The data included in my literature review revealed contrasting results of the relationship and interactions between siblings. On the one hand, siblings were reported to be supportive and accepting, even overprotective and caring over the other with albinism (Lund, 2001). On the other hand, significant discussions were also discovered about the negative experiences of PWA from their sibling that even perpetuated to physical violence (Aborisande, 2021). The report of negative attitudes and behaviours on PWA from siblings often coincides with the discussion of negative attitudes and behaviours displayed by parents and other relatives. It may be that the attitudes and behaviours exhibited by the parents and other grown relatives influence how siblings view and interact with their siblings with albinism.

The caregiving responsibility of siblings of PWA was also a strong finding in the literature I reviewed. They may be expected to take care of their sibling with albinism, especially as parents may not always be present (Lund, 2001). However, siblings experience stigma and discrimination by association as well as trauma due to the negative responses from the community (International Federation of Red Cross and Red Crescent Societies, 2009). Affiram et al. (2019) and Kromberg (2018b) suggested that siblings be provided with social and psychological support to ensure that their voices are heard and that their health and well-being are addressed.

Chapter Two Summary

In summary, this chapter described the existing knowledge about siblings impacted by albinism through a literature review. It showed that there are limited studies that focus on sibling experience, however evidence from relevant articles provided insight on the experiences of siblings within the family and in the community. Overall, these findings reveal the need to hear the firsthand experiences of PWA and their siblings. The relationship between siblings is unique on its own. Centring it within the context of albinism in Africa will contribute to the limited literature on how siblings are impacted by albinism, including the challenges they face and how they can best be supported. The following chapter will present the methodology of this thesis, including the methods for participant recruitment, data collection, and analysis.

CHAPTER THREE: RESEARCH METHODS

The purpose of this study was to explore the experiences of siblings impacted by albinism in the African context. To gain personal and direct insight, a qualitative approach was chosen as the methodology. This approach also provided an opportunity to analyse the social, political, economic, and historical dimensions that impact their individual experiences (Polit & Beck, 2020). In this chapter, I present the research methodology followed by the research design, sampling strategies and characteristics, data collection and analysis process, ethical considerations, scientific quality, and study limitations.

Research Design

This study was a qualitative research design to align with the nature of the research purpose and objectives. Acknowledging the unique experiences of siblings impacted by albinism and the complexity of sibling relationships, Interpretive Description (Thorne, 2016) was chosen as the methodology to generate knowledge relevant to a clinical context. Developed by nursing scholars, Interpretive Description has been increasingly used by healthcare providers as a way to capture a population’s subjective experience through identifying themes and patterns while acknowledging the differences between individuals to inform practice (Hunt, 2009). Interpretive Description strives to address the limitations of traditional qualitative methods (such as Grounded Theory, Ethnography, Phenomenology) (Thorne et al., 1997) in answering complex questions relevant to health disciplines about the experiences of health and illness from “holistic, interpretive, and relational perspectives” (Burdine et al., 2020, p. 336). Interpretive Description aligns with a naturalistic inquiry: (1) It acknowledges that reality is contextual, complex, and subjective; (2) the researcher and the subject of inquiry interact and influence one another; and (3) the theory must be grounded in the data obtained (Thorne et al., 2004). It is a methodology described to be a noncategorical qualitative research in which the approach can be re-evaluated and revised as the research progresses and influenced by analytical frameworks and various contexts at play (Burdine et al., 2020). Interpretive Description was selected because part of the objectives for this study is to contribute to the healthcare knowledge not only to the study of albinism but also in the context of disability in Africa, exploring further how the physical and social circumstances of persons with a disability impacts their siblings and the ways that nursing and other healthcare providers can better support siblings and their families. I will describe in detail in later sections on data collection and analysis, my research design also included dyadic interviews and Adapted Dyadic Analysis (Collaço et al., 2021).

Trauma-Informed Research

Recognizing the varying degrees of human rights violations experienced by PWA and their families, I considered it important to embed a trauma-informed lens throughout the study. Trauma is an individual's response to harmful events or experiences like disasters, violence, or accidents, as well as "extraordinary processes of lives and relationships, including abuse, neglect, betrayal and relational dynamics" (Isobel, 2021, p. 1457). Trauma is an experience that overwhelms one's capacity to cope (Nonomura et al., 2020). It can impact an individual's emotional and psychological well-being and the physical body. Trauma resides in and throughout the body, "stored as sensation such as pain or tension, or is a lack of sensation like numbness" (Dietkus, 2022, p. 28). A key aspect of trauma is that everyone is impacted in different ways and approaches need to have contextual considerations.

Trauma-informed care/practices started in medicine and patient care in the 1970s as a way to acknowledge the traumatic events or experiences when diagnosing or treating patients (Bruice et al., 2018; Dietkus, 2022). Trauma-informed care/practices occur when one recognizes, understands, and considers how potential traumatic experiences can be triggered, influenced, created, or replicated during the interactions (Isobel, 2021). This approach requires an individual to constantly have an awareness, sensitivity, and openness to the different contexts. This study followed the Centre for Disease Control and Prevention’s (CDC, 2020) trauma-informed approach. In Canada, this has been integrated in public health through a module for research ethics (Nonomura et al., 2020). The approach has six guiding principles: (1) safety, (2) trustworthiness and transparency, (3) peer support, (4) collaboration and mutuality, (5) empowerment, voice, and choice, and (6) cultural, historical and gender issues. These principles guide researchers to reflect on the ethical dimensions when conducting research, assessing the individuals’ safety, promoting respect, autonomy, and open-mindfulness, and having the necessary methods and tools to prevent or reduce unexpected distress.

Figure 1: Six Principles to a Trauma-Informed Approach (CDC, 2020)

Trauma-informed approaches have only been recently applied to research methods (Day, 2018; Dietkus, 2022; Petrone & Stanton, 2018). Trauma-informed research promotes ethical and empowering interactions with individuals (Day, 2018). It acknowledges not only the attitudes, behaviour, and lived experience of the individual, but also the social circumstances in which their day-to-day lives take place such as social structures, community environment, and relationships that frame the opportunities and challenges they face (Nonomura et al., 2020). A trauma-informed perspective is directed by much more than the physical manifestations of force or aggression but also less tangible institutional processes, practices, and policies that produce their own threats to the well-being of people. Integrating a trauma-informed approach for this study meant that, in each stage of the research process, a more conscious effort was made to recognize the signs and impact of trauma, understand potential paths to recovery, and seek to actively resist the re-traumatization of individuals (Shimmin et al., 2017).

I implemented the six principles of the CDC's (2020) trauma-informed approach in each of my research processes and the following are examples. Addressing safety, I was cognisant about the impact of trauma on my participants not only the psychological risks of sharing difficult experiences, but I was also conscious about the threat to their physical safety. I mitigated this threat by asking participants to locate a private space for the interviews, and acknowledging the less tangible institutional structures, including the discrimination and exclusion they may have encountered. I applied trustworthiness and transparency by disclosing to my participants my situatedness as a PWA myself but that I grew up in the Philippines and I had not experienced the extent of human rights violations they encountered. Peer support was carried through as PWA who were invited to chose which of their siblings would join them in this study, thereby involving a peer support person. I also aimed to build strong rapport prior to conducting the interviews, facilitating a safe and respectful environment.

The fourth principle relates to collaboration and mutuality. This principle was important to how the interviews were conducted. Although I had an interview guide with questions that aimed to address the objectives of this study, the conversations remained fluid and mutual where participants guided where the conversation was going and how much of their experiences they were willing to share. Moreover, I applied empowerment, voice, and choice. This thesis was intended to contribute to the existing and limited literature on the experiences of PWA and their siblings, however, it also served as a source of strength for them to have given heightened awareness to their unique experiences. Finally, I implemented the sixth principle, cultural, historical, and gender issues. Part of the purpose of this thesis was to examine the cultural, political, social, and historical context of PWA and their siblings, which have been fully explored in my discussion (Chapter Five). I also implemented this principle through my analysis, as I first conducted a thorough analysis of each of the dyads to explore how aspects such as culture and family dynamics shaped their experiences before I analysed across all the dyads.

Recruitment

I recruited fourteen participants through convenience and snowballing sampling. Convenience sampling is a way of recruitment where participants were collected based on how I as the researcher was able to conveniently gather participants, including by location, internet service, or other already formed connections (Polit & Beck, 2020). I was also able to connect with some of my participants through the snowballing sampling technique in which participants were obtained by recommendation by existing/initial participants (Streeton et al., 2004). As Project Coordinator of a research project focusing on albinism, my role includes connecting with community partners and conducting interviews. I have benefited from our research team’s connections with PWA who have siblings and expressed interest in participating in this research. Although convenience and snowballing are not the most preferred method of obtaining a sample (Edgar & Manz, 2017), recruitment methods were limited by the ongoing impact of the COVID-19 pandemic. I had to rely on recruiting through online platforms. I created a virtual flyer (see Appendix D) for the purpose of posting it on social media to assist me in gathering participants. I included my profile account name on multiple social media platforms like Facebook and Instagram, and I provided my phone number on WhatsApp and email (my contact information on this thesis was removed for confidentiality). Because convenience and snowballing sampling yielded a sufficient sample, I ultimately did not need to use social media to gather participants.

Initial connections occurred through email or WhatsApp with the sharing of the Recruitment Letter (see Appendix E; my supervisor's and my contact information were provided in the letter, but they were removed from this version for confidentiality), as this was the most convenient way to connect with potential participants. Recognizing that many families have more than two siblings, the composition of the dyads was precedence to the person with albinism as to which one of their siblings they would like to participate. This promoted a sense of power for PWA (Caldwell, 2013). As this is an emerging field, the focus was only on interviewing pairs of siblings impacted by albinism. In the future, this line of study should be expanded to triads and the whole family impacted by albinism.

Although this is a relatively small sample size, within the context of Interpretive Description, it was difficult to objectively provide an exact number to justify that a sample size is sufficient. Thorne (2016) asserts that there are infinite variations at play in a clinical context which may progress and shift over time, making it difficult to capture all the elements involved in an experience. With the limited time and resources I had, I am presenting the information I was able to realistically achieve.

I focused on countries in Africa as the majority of health and social concerns for PWA raised in the literature occurs in the said continent (Reimer-Kirkham et al., 2019). The setting was also chosen because of the higher prevalence of albinism in the African continent (Kromberg et al., 2020). Participants' ages ranged between nineteen and fifty. Participants were included if they lived in a country in Africa or have lived in a country in Africa for at least five years with an African heritage. Minors were excluded from the study because of issues that could have arisen pertaining to ethical approvals for minors and the need for participants to have the ability to articulate their lived experiences. Also, a maximum age of fifty was decided to capture more current and relevant data. The age range allowed me to gain insights from childhood through to adulthood. Limiting the age range in this way also allowed me to capture the current heightened awareness to the safety and security concerns of PWA and the rise in different measures implemented by government and national and international organizations to address those concerns. Those excluded from the study were individuals who were not fluent in English. Africa is diverse in many ways including languages. It is estimated that there are about 1,000-2,000 languages spoken in Africa (Harvard University, n.d.). Although having perspectives from across Africa would have been ideal, the language restriction was decided upon in consultation with my supervisor. Because of the short timeline, limited resources, and focused scope for this study, it would have been challenging to find a qualified interpreter in each location and to have research materials translated into participants' local languages. In total, I recruited seven dyads (fourteen participants) from five countries: Ghana, Nigeria, South Africa, Tanzania, and Zambia. Virtual recruitment as well as data collection, which will be discussed in the following section, occurred in a ten-week period during the months of October, November, and December of 2022.

Data Collection Procedures

After the initial connection with my participants through email or WhatsApp, we set a date based on their as well as their sibling's availabilities. Each participant was asked to secure a private space for the interview. When we connected during the scheduled time, I introduced myself as a person with albinism and a nurse from Canada but have grown up in the Philippines. I provided background on my involvement in an international albinism and human rights research project and shared information about what my thesis was about. Because my interactions with the participants were all virtual, I aimed to build a strong rapport with my participants prior to their interviews so that they would feel comfortable during it. Then, a consent form (see Appendix F; my contact information as well as my supervisor's were provided in the form but they were removed from this version for confidentiality) was explained with each participant prior to the interviews. They were informed that their participation was voluntary, and no consequences were placed upon them or their family members if they refused to participate. They were made aware that they could skip a question if they were uncomfortable answering them. If they felt that they were not able to continue or presented signs and symptoms of distress, they were informed that the interview would be stopped immediately. A stipend of $25 USD was provided for each participant for their time and to cover the cost of the data/internet used. This rate was also used in our *Mothering and Albinism* project for interviews in Tanzania, South Africa, and Ghana, and recommended by our local partners. Participants were informed that if they withdrew their participation, they were still able to keep the stipend.

The data collection method included semi-structured open-ended individual interviews with each participant as well as a dyad interview with related siblings (see Appendix G for the interview guides). Interviews as a form of data collection are the most common method in qualitative research because it is an effective way to capture data from those with first-hand knowledge of a phenomenon (Thorne, 2016). Many aspects of an experience can only be known from someone who has experienced it. This method was the most appropriate as the interviews were conducted virtually due to the travel restrictions during the COVID-19 pandemic. I developed an observation guide (see Appendix H) that I used as prompts to observe verbal and non-verbal communications during the interviews and to take notes on the setting of each participant.

Data collection also included a joint interview with each dyad. This method has been used in qualitative research for more than three decades to observe the overlap and contrast between paired participants. Manning and Kunkel (2015) argued that dyad interviews allow “researchers to see beyond each individual interview and into the meaning, perceptions of reality, and sense-of-being experienced by a dyad” (p. 186). This method was most appropriate because dyadic interviewing recognizes the “interdependent nature of human agency” (Caldwell, 2014, p. 488). In the context of my thesis topic of exploring the experiences of siblings impacted by albinism, I was able to gain two perspectives from one family within a dyad. I gained a better understanding of their family values and culture and how they interacted with one another. Dyad interviews allowed me to observe the verbal and non-verbal interactions between siblings (though this was limited by the online platform). Moreover, this method provided an opportunity for interaction between the dyad participants, allowing for sharing and comparing point-of-views as well as building on each other’s responses (Morgan et al., 2013; 2016). During the interviews, there were circumstances where one sibling was more conversational and shared more insights than the other. My supervisor and I implemented strategies, such as alternating which participants in the dyad were prompted to answer the questions or repeating the question to the other sibling so that each member in the dyad was given the opportunity to speak.

The ordering of the individual and dyad interviews was scheduled to accommodate for my participants’ other important commitments, work, and our difference in time zones. I first interviewed the sibling with albinism, and then conducted the dyad interview with their sibling. I then finished with the individual interview with the other sibling. This method was convenient for them so that one sibling was not waiting on the other to finish their interviews. As I interviewed the PWA, I was able to gain perspective of their experience first. Both individual and dyad interviews were conducted via Zoom or WhatsApp for about 60-90 minutes, cumulatively for each participant. Numerous studies have recently been conducted regarding the use of audio and video platforms in qualitative research and interviews (Oliffe et al., 2021; Salam & Giri et al., 2021). Platforms like Zoom allow researchers to connect with their partners and participants while abiding by the COVID guidelines (Salam & Giri, 2021). Oliffe and colleagues (2021) stated that their participants were open and willing to share their stories as they felt that connecting through the internet felt safe. There was a sense of social connection but without the physicality of being in the same space, which can cause anxiety or apprehension. Virtual interviews were convenient for my participants as they had access to the internet, and they were able to complete the interviews in the comfort of their chosen environments. The video and audio functions allowed me as the researcher to not only hear the tone and changes to the voices of the participants but also see facial expressions and other physical gestures as well as environmental surroundings. However, I had to conduct two dyads' interviews with just the audio function because of poor internet connections. Overall, this method of data collection was cost-efficient for me as the researcher because conducting a multi-site data collection virtually meant there were no travel expenses.

I kept a digital reflexive journal throughout the research process to document observations and notes, and these also served as fieldnotes (Meyer & Willis, 2019). The journal accounted for my reflexiveness, experiences, and progress, recognizing my personal connection with the topic of interest. This journal helped me to situate myself as an insider, who has a personal experience as a person with albinism with siblings, as well as an outsider, knowing that individual contexts greatly vary and are different from my own (Thorne, 2016). I wrote my fieldnotes soon after each interview was completed to capture as much details as possible. Each participant was asked to complete a demographic form (see Appendix I) to obtain a general background of the participants. After the interviews, participants were sent a Debriefing Letter (see Appendix J) that contained my contact information as well as the contact information of my supervisor (which were removed from the appendix version for confidentiality) and the Ethics Board. During the data collection process, I debriefed with my supervisor after each dyad interview to review the effectiveness of the interview guides and what key insights were gained.

Analytical Process

The analytic process characteristic of Interpretive Description is inductive and thematic. Thematic analysis is a process of identifying, coding, and categorizing the patterns of the data (Beck, 2013; Thorne, 2016). I took additional direction from the Framework Method for the analysis of the dyadic interviews, to account for siblings' individual and shared perspectives. The Framework Method falls within a broad family of thematic analysis to identify commonalities and differences in qualitative data (Gale et al., 2013). Then, it moves to making relationships within the data, and therefore aiming to provide descriptive and/or explanatory conclusions clustered around themes. The Framework Method is an approach to manage and analyse qualitative data through summarization of a series of themed matrices, allowing the researcher to analyse the data by case and theme.

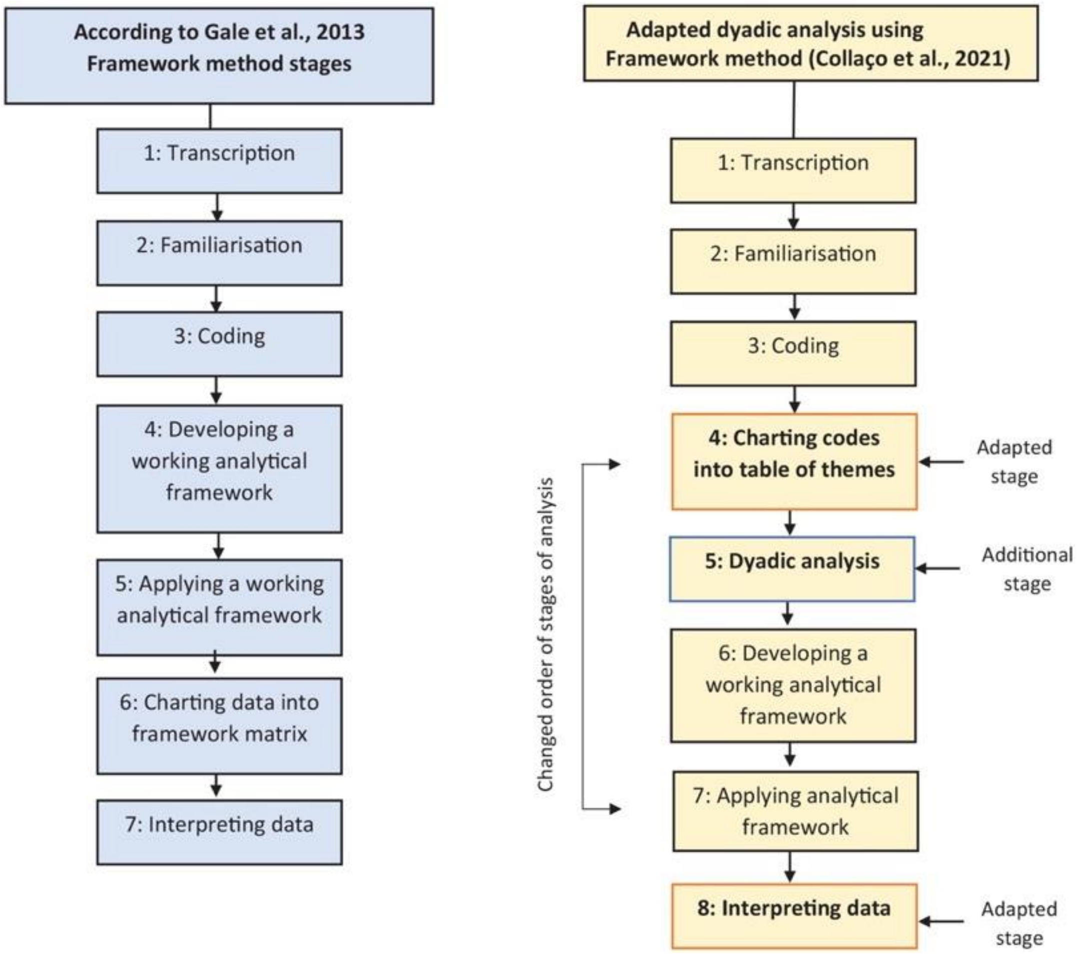


Figure 2: The Framework Method (Gale et al., 2013) on the left and the adapted dyadic analysis of the Framework Method (Collaço et al.'s 2021) on the right.

Given that this study involved dyadic interviews, I needed to lean towards a dyadic analysis. As seen in Figure 2, Collaço et al. (2021) adopted the Framework Method to integrate a dyadic approach, calling it the Adapted Dyadic Analysis Using the Framework Method (Gale et al., 2013; Ritchie & Lewis, 2003). For the analytic phase of my thesis, I further modified Collaço et al.'s (2021) model to apply Caldwell's (2014) idea of recognizing the interdependence and interconnected nature of people which is, in this case, each dyad (as seen in Figure 3).

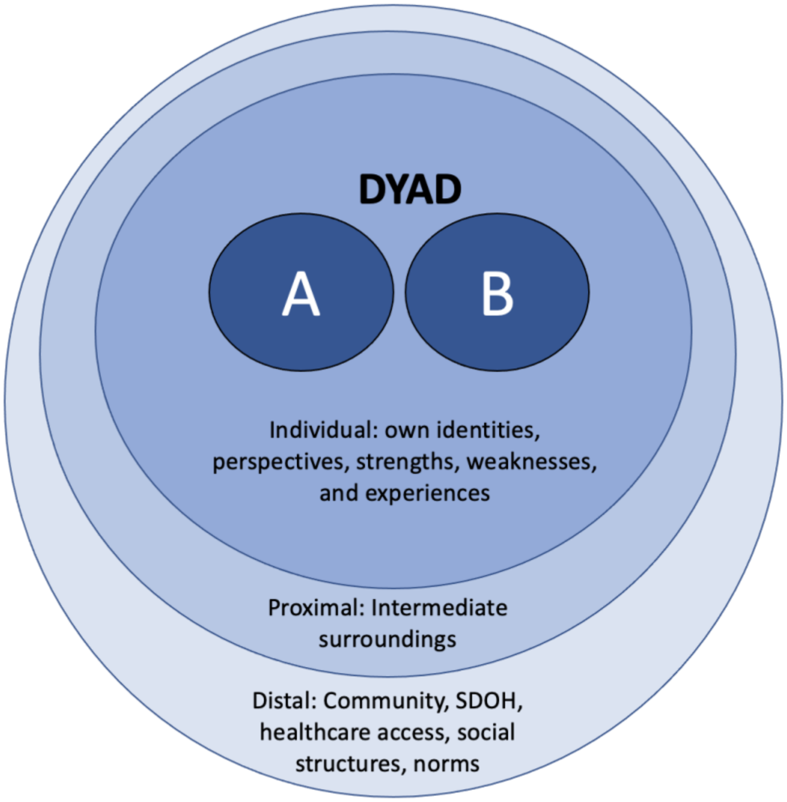
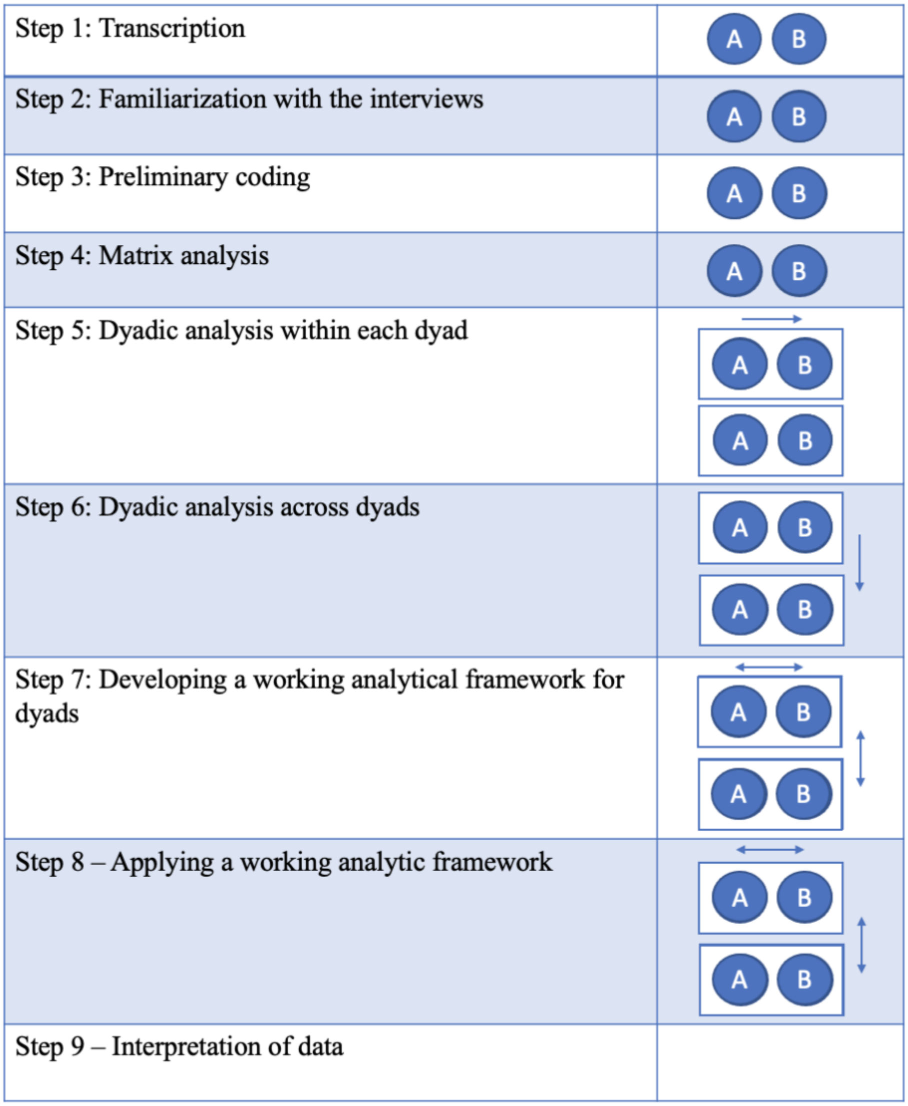


Figure 3: The Context Influencing a Dyad

Rather than attempting to control or create a division between people, the dyad methodology raises the need to value the interconnectedness, non-independent relationships, thereby needing to contextualize each dyad (Wittenborn et al., 2013). The unit of analysis, especially with my study being joint and individual dyad interviewing, is the dyad itself. Collaço et al. (2021) proposed an eight-step process for a dyadic analysis. My modification of their framework involved dividing their step five into two parts to clearly acknowledge the relationship of each dyad before conducting an analysis across all dyads. Table one below and the next section describes my analytic process.



Step 1: Transcription	A B
Step 2: Familiarization with the interviews	A B
Step 3: Preliminary coding	A B
Step 4: Matrix analysis	A B
Step 5: Dyadic analysis within each dyad	A B A B
Step 6: Dyadic analysis across dyads	A B A B
Step 7: Developing a working analytical framework for dyads	A B A B
Step 8 – Applying a working analytic framework	A B A B
Step 9 – Interpretation of data	

Table 1: Modified version of the adapted dyadic analysis of the Framework Method (Collaço et al.'s 2021)

Step One: Transcription

The first step was transcription. Each interview was audio-recorded and transcribed in verbatim by myself or a transcriptionist (see Appendix K for the Confidentiality Agreement Form; my contact information as well as my supervisor's were provided but they were removed for confidentiality). It was important that I transcribed some of my interviews to immerse myself in the analytical process. Data was stored in a password-protected computer to ensure data protection. A cloud-based storage, ownCloud, was used to securely share data with my Committee and transcriptionist.

Step Two: Familiarization of the Interviews

Once the interview was transcribed, I reviewed each transcript by listening to the audio recordings to ensure they were accurately transcribed. This listening also allowed me to gain awareness of the context of each participant's surroundings and hear their voices again in this phase of the analytical process. I reviewed my fieldnotes for my reflections of the interviews and other insights that were not shared during the recordings of the interviews. Transcripts were read repeatedly to familiarize myself with all the data.

Step Three: Preliminary Coding

Using an inductive process, I conducted a preliminary coding on all my transcripts to bring out broad themes and patterns present in the data. Coding is the process of identifying essential, interesting, or prominent features in relation to the topic of interest (Polit & Beck, 2020). Preliminary coding occurred concurrently during data collection, together with my supervisor. It allowed us to see how effective the interview guide was, and it provided an opportunity to identify early on what themes emerged. Preliminary coding promoted my deep emersion into my data. This phase enabled me to give my full attention to the perspective of each participant, reading the transcripts as is and without the influence of their sibling as well as the other dyads.

Step Four: Matrix Analysis

The Matrix Analysis included creating a matrix using the broad themes identified during the preliminary coding and guided by this study's objectives. A matrix has a set of themes and data arranged in rows and columns (Averill, 2002). In qualitative research, individual cases are sorted in rows and the themes of data occupy the columns. In my matrix, the rows were arranged in a way that the individual and joint interviews of each dyad were side by side. Themes included were the following: growing up with albinism/growing up with a sibling with albinism; knowledge about albinism; interaction with siblings; experience with parents; family support; family values; household responsibilities; experiences with the community; access to health and social services; and recommendations to support families. As my supervisor reviewed my coding during this phase, the codes remained fluid throughout the organization of the data, recognizing that research is continuously influenced by the context of the participants (Thorne, 2016).

Step Five: Dyadic Analysis Within the Dyad

The next step was conducting an analysis within each dyad. This aspect was crucial in identifying the proximal or intermediate contributing factors that influences the dynamics or experiences of each dyad. Each dyad represented a family in Africa and each family's circumstances differed. Just as each participant in the dyadic relationship varied in age, gender, education, and marital status, each dyad further diverges in family values, traditions, culture, and familiar responsibilities. For my thesis, an analysis occurred across the rows of the matrix to identify themes and patterns between the siblings and identify concordance and discordance between what the siblings contributed during their individual and joint interviews. It revealed the extent of agreement between members of the dyad and identified how albinism possibly changed their experiences (Collaço et al., 2021). As indicated, the unit of analysis was the dyads which considered the relational aspects (social ties, interactions, relationships) and looked at the meaning within the dialogue and how they spoke with each other and about one another (Hudson et al., 2020).

Step Six: Dyadic Analysis Across the Dyads

After I studied each dyad within their context, I conducted an analysis across the dyads. This included going down the columns of the matrix (for example, reviewing each participants' comments about family values). It depicted a description of how siblings included in the study were impacted by albinism in various contexts, including within their family and in the society, which informed the next step of the analysis. Although each participant shared their own stories and perspectives, I needed to recognize the dyadic experiences rather than individualizing my analysis to one participant at a time (Collaço et al., 2021). This method added a layer of dimension to the data. It integrated a third dyadic version where there are individual accounts but acknowledging that "the dyadic version is more than the sum of two individual ones" (Eisikovits & Koren, 2010, p. 1652).

Step Seven: Developing a Working Analytical Framework

My matrix was then imported into NVivo™, a qualitative data management software (Lumivero, n.d.). My supervisor reviewed my codebook during this phase. As opposed to coding per transcript for each of my participants, I coded by dyads which were already in my matrix to better reveal the themes and stories, shifting from thematic to narratives. New themes were devised (see Appendix L for my Codebook) based on this dyadic analysis and the running narratives congruent among all the dyads formed the working analytical framework.

Step Eight: Applying a Working Analytical Framework

Using tables and diagrams (which will be shared in the findings section of this paper) and collaborating with my supervisor, I applied the analytical framework which derived from the matrix created and NVivo™ coding, and combining the insight gained through the dyadic analysis within and across the dyads.

Step Nine: Interpretation of the Data

For the interpretation of the data, I used dyadic analysis to recognize and incorporate the variation of experiences of the dyads, including attitudes and behaviours from their community and access to health and social services. It highlighted the unique impact of albinism on the dyads and the interconnectedness of the experience of the entire family. Following interpretive description, the analytic process was guided by what was in the data (Thorne, 2016).

Ethical Considerations

Ethical approval was obtained before conducting fieldwork, with submission to Trinity Western University’s Human Research Ethics Board (see Appendix M for the Approval Letter). All materials used in this study were reviewed by the Research Board and my Committee. The consent form was reviewed with the participants prior to the interviews. They were informed that they were able withdraw from the study at any time up until their de-identified transcripts are embedded into the data, as at that point, it would be impossible to identify what their contributions were. I obtained verbal consent with a clear statement of “I agree to participate.” They were informed that they could choose to not answer a question if they did not feel comfortable sharing that information. Acknowledging the implementation of trauma-informed research and highlighting the human rights of PWA and their family, an emphasis was placed on empowerment, autonomy, and freedom. Given the potential risk of the remembrance of traumatic events, I observed for statements and behaviours that could suggest that the interview was stressful or traumatizing (Draucker et al., 2009). As nurses, the need to elicit support and care is important even in research when interacting with various individuals (Salma & Giri, 2021). Thus, building a strong rapport with participants was crucial before starting the interview so that they would feel more at ease in sharing their experiences. They were asked if they had a support person with them such as a family member or a friend. Resources for debrief were identified in the area prior to fieldwork for cases in which participants may experience distress.

The privacy and confidentiality of the participants were of utmost importance for this research; additional risks arose when using virtual platforms to conduct interviews. I mitigated these risks as much as possible. The interviews were conducted with a password-protected computer and cellphone. When using the Zoom application, security was enhanced by (1) enabling the waiting room, (2) requiring a passcode to enter the virtual meeting, and (3) using the "lock meeting" feature (an added security that keeps new participants from joining the virtual meeting space). Participants were asked where they were located and whether there were accompanied by individuals during the interviews.

All documents were stored in a password-protected computer. The ownCloud software was used to store data and share documents. It had an embedded password and was only accessible to the transcriptionist and my Committee. All transcripts were reviewed carefully to ensure that participants' names and identifying locations were removed. The recordings were deleted from the recording device after they were transcribed and reviewed.

Scientific Quality

To enhance the rigor and trustworthiness of this study, I applied Thorne's (2016) four evaluation criteria, which have been based on general principles widely accepted in qualitative research: (1. Epistemological integrity refers to demonstrating the sense of a "definitive line of reasons about assumptions made about the nature of knowledge through to the methodological roles by which decision about the research process are explained" (Thorne, 2016, p. 233). It is concerned with whether the findings were of assumptions implicit to the research design or of predisposed knowledge of the researcher. Recognizing that, as the researcher, I interacted with the subject of inquiry (participants) and have had knowledge and experience on the topic, I continued to be cognisant about how I influenced each step of the research process and have thoroughly disclosed my positioning in this paper. My fieldnotes were useful to reflect on my beliefs, practices, and overall experiences, further separating but accounting for my perceptions. Likewise, representative credibility refers to the ability of the theoretical claims presented to be consistent with the manner of which the studied phenomenon was sampled (Thorne, 2016). During the interviews, I asked for clarifications and observed how the siblings interacted with each other. Through conducting two interviews, an individual and a dyad interview with each participant, I was able to re-affirm statements. I also applied the constant comparative method where I coded and analysed at the same time, utilizing multiple resources such as relevant literatures and the expertise of my Committee to gain a better understanding and corroborate findings (Kolb, 2012).

Next, analytic logic is described as explicit to "the reasoning of the researcher from the inevitable forestructure through the interpretations and knowledge claims are made on the basis of what was learned in the research" (Thorne, 2016, p. 234). I kept a thorough record of my encounters with the participants by way of the transcripts (which were in verbatim) and my fieldnotes. I used a step-by-step analytical framework taking into account the context of each of the dyads. The fourth evaluation criterion is interpretive authority, where the finding presented is trustworthy and ones that might be "shared or common in nature" (Thorne, 2016, p. 235). I used a coding method of generating themes and patterns to facilitate interpretation within the data (Polit & Beck, 2020). The codes were created based on what was being read in the transcripts. However, I acknowledge that this study spans much of Africa where the cultures, values, and other social circumstances vary greatly and are further differentiated by diverse families and communities. I cannot generalize my findings to the whole of Africa. I further recognize that this study involves the “real” day-to-day experiences of PWA and their siblings. It is their voices I wish to highlight in ways that respect and honour them and the narratives they chose to share.

Limitations

Since the data collection occurred virtually, experiences from participants living in remote areas with no access to internet services were difficult to reach. Salma and Giri (2021) explained that, because of the pandemic, virtual data collection caused further divide between those who are able and not able to participate in research. The untold stories of those most vulnerable must also be heard. It was unavoidable, however, that internet connections posed a challenge. Some countries in Africa like South Africa are facing constant load shedding or blackouts that impede the strength of the internet (Wroughton, 2022). At some points, videos were switched off to improve the internet signal or by preference of participants. The understanding of the context was limited, therefore, by what I was able to see when the video camera was on and what the participants chose to disclose (Oliffe et al., 2021). News, social media, and google maps were utilized to gain a better understanding of the places where participants resided. For example, I used the street view on Google Maps to see the physical surroundings of the dyads.

Furthermore, my participant sample is not representative of the population in Africa, nor the PWA population (my sample will be introduced in the following chapter). Eleven out of my fourteen participants have or are in the process of completing some level of post-secondary education. All but one dyad grew up in an urban or sub-urban setting. All participants disclosed that they are of Christian faith. This limitation is largely due to the virtual nature of the research process, needing to recruit and conduct data collection virtually.

Using dyadic interviewing had its strengths, but it also had its challenges. On the one hand, conducting a study involving two siblings from the same family meant that I was able to observe their relationship and hear from both perspectives (PWA and their sibling). However, on the other hand, dyad interviews meant approaching two participants who were willing to be interviewed together. The participants I first reached out to were PWA and they were given the option to choose which of their siblings to approach and include in this study. A level of comfort and safety was involved for each participant in the dyad to agree to be interviewed together. Yet, from the literature review I conducted, I knew the relationship between siblings may not always be positive. My study does not capture these other less supportive relationships and circumstances.

The inclusion criterion of participants who spoke fluent English was also a form of limitation. With this thesis having a focus on the whole of Africa, translating all research materials, and finding a qualified interpreter for each location of the recruited participants was not feasible, all the more so because my presence was only virtual. This study was also limited by a relatively small sample size because, as a thesis, this is a small-scale project. Nonetheless, I hope that this thesis will encourage future studies to focus on the experiences of siblings impacted by albinism as this is an area that has not been well researched.

Chapter Three Summary

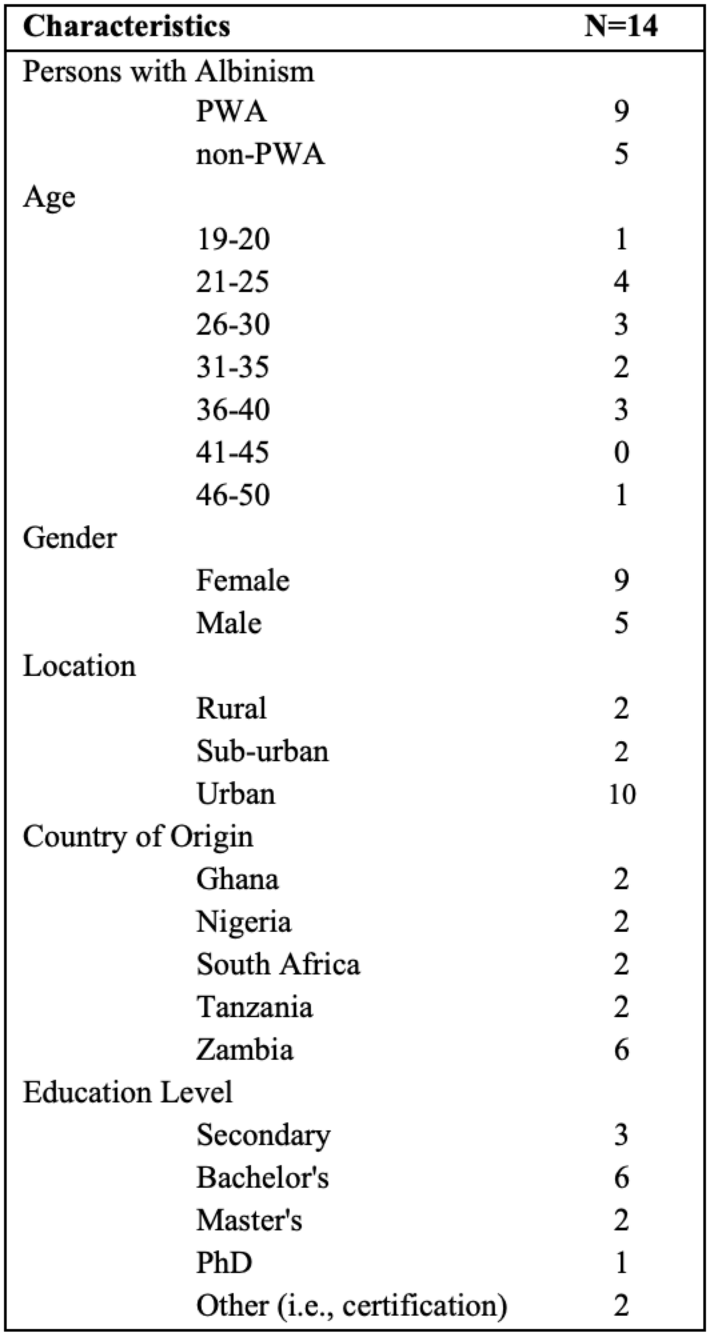
In summary, this chapter described the methodology of this thesis. I conducted a qualitative study using Interpretive Description (Thorne, 2016) with a Trauma-informed approach (CDC, 2020). Ethics approval was obtained through Trinity Western University’s Ethics Board. I followed convenience and snowballing methods to recruit my participants virtually. The method of data collection was through individual and joint virtual interviews with each dyad. Each interview was audio-recorded and then transcribed in verbatim and reviewed. Dyadic data analysis was conducted using a modified version of the adapted dyadic analysis of the Framework Method (Collaço et al., 2021). Ethical considerations and study quality were assessed and described. The study’s findings are presented within the next chapter.

CHAPTER FOUR: FINDINGS

In this chapter, I describe the findings of this thesis from insights gathered from seven dyads (fourteen participants). The objective of this thesis was to explore the experiences of siblings impacted by albinism in the African context. I first provide some context by describing the characteristics of my participants. Then, I present my findings through dyadic thematic analysis with four themes: (1) *Internalizing Processes: Persons with Albinism and Siblings*, (2) *Normalizing Responses: Family Interactions, Support and Responsibilities*, (3) *Stigmatizing Experiences: Community Context*, and (4) *Encompassing Support: Needs of Families Impacted by Albinism*. The interpretation and discussion of these findings will follow in Chapter Five.

Participant Characteristics

The focus population for this study was siblings impacted by albinism with a total of seven dyads (fourteen participants). In my sample, there were two dyads where both siblings have albinism and five dyads with one PWA and a sibling without albinism. In total, nine participants are PWA and five do not have albinism. The seven dyads were from five countries: Ghana, Nigeria, South Africa, Tanzania, and Zambia. Twelve participants currently reside in Africa and two have lived in a country in Africa for at least five years. Five dyads described growing up in an urban setting, while one dyad grew up sub-urban and one dyad grew up in a rural setting. Three participants have not finished high school, six have their bachelor’s degree (included here are three participants who are in the process of obtaining their bachelor’s degree), two have their master’s and one participant achieved a doctoral degree. All participants are of Christian faith.



Characteristics		**N=14**
Persons with Albinism		
	PWA	9
	non-PWA	5
Age		
	19-20	1
	21-25	4
	26-30	3
	31-35	2
	36-40	3
	41-45	0
	46-50	1
Gender		
	Female	9
	Male	5
Location		
	Rural	2
	Sub-urban	2
	Urban	10
Country of Origin		
	Ghana	2
	Nigeria	2
	South Africa	2
	Tanzania	2
	Zambia	6
Education Level		
	Secondary	3
	Bachelor's	6
	Master's	2
	PhD	1
	Other (i.e., certification)	2

Table 2: Demographic Profile of Participants

Description of the Dyads

In this section, I introduce the seven dyads that consented to participate in this study and share their experiences. The dyads are labelled alphabetically (Dyad A, Dyad B, etc.), and each participant is indicated with a pseudonym to protect their privacy. The first letter of the pseudonym of the participant corresponds to their dyad group (for example, Dyad A: Adla and Anna; Dyad B: Belle and Bridget).

Dyad A: Adla and Anna

Dyad A comprises of two siblings who grew up in an urban city in Africa (I am intentionally not mentioning their specific country because of the positioning of my participants that can make them identifiable). Adla and Anna are both women. They are from a group of three siblings, and all have albinism: Adla (PWA) is the youngest and Anna (PWA) is the oldest. They have a cousin who has albinism from their mother's side of the family. Adla (PWA) went to a boarding school during her elementary and high school years and is on her way to finishing her bachelor's degree. Anna (PWA) also went to a boarding school for a few years before she graduated from high school, and she has since finished a master's degree. Anna used to work in an albinism organization in Africa, and at the time of this interview, worked in a human rights organization. Because they both studied at a boarding school, they acknowledged that they spent limited time together in their childhood years. Adla went home a couple times a year during her time in boarding school. Their father worked in an organization and their mother owned a store. Adla (PWA) and Anna (PWA) live in the same city but not in the same household as Anna (PWA) has a husband and children now. They meet during special events and talk on the phone from time to time.

Dyad B: Belle and Bridget

Belle and Bridget are siblings in Dyad B. They grew up in an urban city in Africa. Belle and Bridget are both women and they have albinism. They are from a four-sibling family: Belle (PWA) is the second-born and Bridget (PWA) is the third-born child. Their two other siblings do not have albinism and there are no other known relatives with the condition. Their mother worked as a domestic worker in a different city, so Dyad B and their siblings grew up with their aunt. Their father died when they were children. Although they lived in the same house, the dyad did not go to the same school. Belle (PWA) moved schools a few times when she was younger, but it was unclear to her as to why. Belle (PWA) and Bridget (PWA) did not finish high school. Belle (PWA) is a homemaker and Bridget (PWA) is a businesswoman. They both have husbands and children and are currently living in different cities.

Dyad C: Carl and Coral

Dyad C includes Carl and Coral who grew up in a rural area in Africa. Carl is a man with albinism and Coral is a woman who does not have albinism. Their family has three siblings: Carl is the first-born child and Coral is the middle child. Carl is the only person with albinism in their family. According to Carl (PWA), they have a distant relative with albinism, but he has not met this relative. They lived in one household with their parents. Their mother worked in farming and trading while their father worked in security services. Carl (PWA) has his master’s degree and has a leadership role in an albinism organization. Coral has a diploma, and she is currently a homemaker. She is single with two children. Carl (PWA) moved to an urban city when he pursued his education and remained in the city for his employment. Coral is living in the area they grew up in. They stay connected through phone calling and seeing their family during the holidays.

Dyad D: David and Donna

David and Donna are siblings in Dyad D. They grew up in an urban area in Africa. David is a man with albinism and Donna is a woman without albinism. They originally had nine siblings, but their eldest and youngest sibling died. Their youngest sibling who passed away had albinism. Thus, they are from a seven-sibling family: David (PWA) is the second to last-born and Donna is the sixth sibling of the family. There are no other known relatives with albinism. The dyad and their siblings grew up in one household with their parents, but their older siblings moved out when they were old enough. Thus, David (PWA) and Donna, as younger siblings, became close as they spent their childhood together. Their mother is a housewife and their father worked in the Ministry of Health. David (PWA) is currently living in a different city as he is pursuing a bachelor’s degree. Donna is a homemaker and is raising a child as a single mother, and she has a diploma. David (PWA) works in an albinism organization. Although he lives in a different city, he goes home to spend time with his family during his vacation breaks from school.

Dyad E: Edward and Erica

Dyad E comprises Edward and Erica. They grew up in an urban city in Africa. Edward is a man who has albinism and Erica is a woman who does not have albinism. Their family has six siblings: Edward (PWA) is the second-born and Erica is the youngest child. Edward (PWA) is the only person with albinism in the family and has no other known relatives with albinism. Their parents separated when they were children. Edward (PWA) and another sibling grew up with their grandparents and the rest lived with their parents. Their father worked in security services and their mother worked in trading. Edward (PWA) finished a bachelor’s degree and has a leadership role in an albinism organization. Erica is about to finish high school. Now, Edward provides livelihood for his family and lives with Erica and their other siblings.

Dyad F: Faith and Freya

Faith and Freya are siblings in Dyad F. They grew up in an urban city in Africa. Faith and Freya are both women, but Faith is the only one with albinism. They are from a four-sibling family: Faith (PWA) is the youngest and Freya is the second oldest child. They have three cousins with albinism. All siblings lived in the same household with their parents. Their father worked in an organization and their mother sold cosmetics. Faith (PWA) is studying at a university for a bachelor's degree and works in an albinism organization. Freya has a bachelor's degree and owns a clothing store. She is now married with children. Faith (PWA) is studying in a different city but goes home during vacation breaks to be with family.

Dyad G: Gabriel and Grant

Dyad G includes Gabriel and Grant. They grew up in a sub-urban town in Africa. They are both men, and Gabriel is the only one with albinism. Including the dyad, they have seven living siblings. Grant is the second oldest sibling and Gabriel (PWA) is the youngest. They were originally nine siblings but two siblings with albinism died young. Currently, Gabriel is the only person with albinism in their immediate family. They have a distant relative with albinism, but they have not met this individual. All siblings grew up in one household with their parents, but Grant went to boarding school. He and another sibling moved to Europe in the early 1990s. Gabriel (PWA) spent more time with his younger siblings growing up. Both parents were teachers but also worked in farming. Gabriel (PWA) has a doctorate degree and has since also moved to Europe (different country from Grant). Both Gabriel (PWA) and Grant are now married and have children of their own. Gabriel's (PWA) studies in part focus on albinism. Grant owns a company with their older sibling. Although they live in different countries, they connect almost daily on the phone.

Thematic Analysis

Conducting a thematic analysis on the individual and dyad interviews, four themes emerged. In Theme One, *Internalizing Processes: Persons with Albinism and Siblings*, participants described inner mental processes in relation to the impact of albinism. In Theme

Two, *Normalizing Responses: Family Interactions, Support and Responsibilities*, the dyads highlighted the overall influence of their families through their day-to-day interactions and how they provide support to one another. Theme Three, *Stigmatizing Experiences: Community Context*, relates to the stigma and discrimination experienced by PWA and their siblings due to the continued existence of deeply rooted cultural beliefs and practices associated with albinism. Theme Four, *Encompassing Support: Needs of Families Impacted by Albinism*, illustrates the explicit and implicit insights into the needs of PWA, their siblings, as well as their families overall. These themes, taken together, point toward the need to address the challenges that PWA experience to support families impacted by albinism.

Internalizing Processes: Persons with Albinism and Siblings

All fourteen participants recounted experiences of a personal and inner conflict associated with albinism. This mental and internalized process was experienced separately, apart from the other sibling in the dyad. This internalization was experienced by PWA and their siblings.

Persons with albinism

PWA in this study shared the psychological and psychosocial impact of having albinism. Concerns raised by PWA were primarily due to being different from other people, with questions such as: *Why me? Why do I have albinism?* PWA had a personal and individual journey, typically during childhood and adolescence, toward developing an identity and, at the same time, acceptance of themselves as a person with albinism. Reflecting on when she was a child, Belle (PWA) explained.

> I am an emotional person. I think it's too hard. I also want answers to know why [I am] like this, and it really seemed like my mind locked… I have to work with myself, I say 'no, maybe I am wrong'. I like to think it's too hard.

She explained she had to be strong to overcome her emotions and perceptions regarding her condition:

> I change the way I take things. I make myself strong, I read the Bible, and then I tell myself 'go to church'. I started to increase my self-confidence once again to become something. I tell myself, even other people [with albinism], they have all sorts of problems but they do not take it personal. So, I now [work on my] self-motivation. I listen also to people who motivate. I listen more radio and then I like to read more. If some people are like me, how did they survive? How did they become the way they are?

She gave herself these "pep talks" and would draw strength and encouragement from her faith, the books she read, and the social media. Her sister who also has albinism shared the same journey. Bridget (PWA) did not understand why she was different from other people when she was younger. She had to propel herself to understand the situation. For her, she realized, "I cannot change everything… what God has created... I never ask God, 'God just make me and treat me like [a normal skinned person]'. There's [none of that]. It's only God who knows why I must be like this." Being one of the only few PWA in the community, especially as children, it seems that PWA internalized their difference, impacting the way they viewed themselves. They searched for explanation, including spiritual understanding, about why they are physically different from others.

Moreover, PWA internalized the health complications associated with albinism. Understandably, participants expressed great worry about their visual impairment, especially as it affected their academic performances. They also shared similar concerns about their vulnerability to skin cancer. Within this context, they expressed the concern about their physical appearance. For example, Anna (PWA) explained,

> I hated the spots on my skin. I was very conscious of them. And I have many of those. My worry was nobody would hang out with me because of how I looked. Because I was conscious of how people would see me, how people would take me. So it came to a point when I meet somebody new, I would tell them in advance, you know, 'I look like this. Are you comfortable with that?' I didn't have to do that but that was how insecure I was because of the way I looked.

Although wearing protective clothing (long-sleeved shirts and pants), hats, and sunscreen would seem to increase the attention and responses they received from the community, they understood that they are required to continue wearing them. Anna (PWA) stated,

> I am aware of the side effects which can occur [when] I do not wear [protective clothing]. So, you just keep on wearing it. Because maybe I grew up knowing how to [be] preventive. So it helps me not care about what other people are thinking.

In understanding what albinism is and knowing that they have a greater risk of skin cancer when not taking preventative measures, especially with the African temperatures, PWA came to normalize and accept that they must apply sunscreen regularly and wear protective clothing and hats.

For all participants with albinism, in many ways, it was difficult to disassociate the psychological impact from the psychosocial impact of albinism because the way PWA viewed themselves having albinism was influenced by how their community responded to the condition. Their main concern was the colour difference of their skin and hair which made them stand out in their African community. For instance, Carl described growing up living with albinism to be of mixed feelings because “one, you found yourself differently among others. So, you feel insecure. You count yourself less because you are different. [But two], you’re unique. It gives a lot of attention growing older.” On the one hand, Carl described that having albinism is a positive thing because he is unique and special. But on the other hand, standing out from the community meant that he feels different, not “normal” and therefore received a lot of attention. PWA in this study shared ample stories of the stigma and discrimination targeted toward them when they were growing up due to the beliefs associated with the condition (this will be further described in Theme Three). Instead of being discouraged, however, the experiences they had when they were younger for the most part fueled their resilience, strength, and even motivation and determination. Faith (PWA) described when she was younger that the

> [Responses by the community] would hurt me, it made me feel as though I was not human or anything, like I am an unwanted person… I came to realize that those same discriminations are the same things that are making me to be strong and to have confidence.

In Faith’s (PWA) case, due to her experiences, she took the initiative to show the community what she is capable of, that she can do anything that others could do. She is currently working on her bachelor’s degree and will one day want to work in the health and social field to support other PWA.

There may also be PWA who were extroverted and often engaged in the community like Edward (PWA). He described himself as

> the type of a guy who had so much self-esteem, self-image… I was very much active… full of confidence and on top of that, I used to sing. I would go to the studio and sing

> when we have got a concert in the community. I used to take myself [there] because I was such type of a guy who never used to care.

He did pay attention to what people around him thought about his condition, rationalizing that they just did not know what albinism was. He concentrated on being visible in the community, showing them that he could sing, participate in various games, and study in school just like other children. It is important to note that all participants with albinism have taken a part on the recent human rights albinism movement in various levels and capacities, with Anna, Carl, David, and Edward (all PWA) working or have worked in an albinism organization. It seemed that they were fueled by the need to educate people about the condition and for others who are growing up with albinism to not have the same experiences that the participants had when they were younger.

As this study included two dyads (Dyad A and B) where both siblings have albinism, it was peculiar to find that they experienced similar internalized struggles but experienced them separately from each other. Anna (PWA), for example, said,

> I focused a lot on my parents. Like why my parents do not have albinism. I have albinism. My dad and mom, they don’t have albinism. But as for us, siblings, we all have albinism. So that brought a lot of questions, like, how come?

Even though they may have siblings with the same condition, PWA still seemed to notice the apparent colour difference around them as they were not among the majority, ones who have fair or dark skin. For her sister, Adla (PWA) experienced “being aware that you are kind of different from others… it can keep you in a state of self-denial.” To overcome this, she stated that she had to “realize herself” and learn what albinism was. During the individual and dyad interviews, participants in Dyad A did not acknowledge that their stories were parallel to one another. When they described their stories, it seemed that their narratives of how they felt about their condition did not intersect, such as confiding with one another regarding their concerns. But it may be due to growing up separately as Adla (PWA) spent a large portion of her childhood in a boarding school. Conversely, participants in Dyad B, although they did not share the same school, they lived in the same home. Belle and Bridget both had albinism, but they also did not share their emotional struggles with each other. Bridget (PWA) disclosed,

> I used to cry. Maybe someone who understands me will come and ask me [why I am crying], but the problem is that I cannot share if I am having a problem. I am just keeping it for myself. I just go outside and cry and cry and cry.

She said that this has been her response since childhood and continues to be so up until now, living with her husband and children.

Similarly, PWA in the other five dyads kept these emotions to themselves. Faith (PWA) shared that her "family would hear. Most of the time, they would [ask me about it], I just hear them, but I would not tell anyone at home. I would just keep quiet about it and forget about it." PWA acknowledged that their siblings and other family members would sense something was bothering them, but they would nonetheless refuse to share their feelings. With Dyad G, Grant, as a sibling of a PWA, acknowledged his brother, Gabriel (PWA), was going through something in school but Gabriel (PWA) kept his concerns to himself. Grant recounted that he would sometimes push his brother to share what he was going through, but Gabriel would respond to him with "I am a big boy now" and "I do not have to talk about it." Therefore, Grant did not know exactly what was happening until he heard about what other PWA were going through in different parts of Africa.

Likewise, findings show that PWA worry about their siblings, afraid that having albinism would impact their siblings' social interactions. Gabriel (PWA) reported the following:

> I gradually started getting worried about the fact that I felt that just being their sibling was having an impact on them, particularly as girls… Every now and then they would come home with friends and sometimes there would be that awkwardness. Their friends not being very comfortable around me, and I felt that would, in some way, make them uncomfortable as well. What really worried me were very specific instances where [my sisters] actually would have male friends who were maybe courting and perhaps were interested in marrying them. And then when they come home to see my parents and I am there. Then maybe a few months after, they are no longer dating and I always felt somehow responsible because it seems as if, you know, the guys were not comfortable getting married into a family that had a person with albinism… I did not want to be the reason why her relationship wouldn't work.

Due to the still existent erroneous beliefs about albinism and distinct colour difference of their skin and hair, PWA may have felt that their condition was a deterrent for their siblings, especially the women, in forming friends or finding partners. Gabriel (PWA), at certain circumstances, felt that he needed to go out of the house to avoid the awkwardness. He never shared this concern, however, with his family.

Siblings of Persons with Albinism

In this section, I will be focusing on the five dyads where one sibling has albinism and the other does not, foregrounding the perspectives of siblings without albinism. Participants explained that they did not have concerns about having a PWA as a sibling. Erica said, "[growing] up with a sibling with albinism feels good because we treat one another equally… It's quite good growing up with my brother and I'm proud of him. I'm just comfortable with him." Because she grew up in the same household as her brother, Edward (PWA), she had "gotten used" to him. As the younger sibling to Dyad E, she had always been around him. Influenced by their upbringings, siblings viewed the other with albinism as "normal" or "equal." For Freya, she described growing up with Faith (PWA) as

> a great thing… growing up with her, it was just a blessing… [but when] she was born... dad was the one [who educated me], cause I was like, 'Huh? We have a baby that's *Mzungu*?' He told us, 'no, in life we have this type of people.' What? So when you sit to her, you should take as if she's more like you. You are the same. It's just the color, which is different.

With education from her parents, she had an immediate acceptance of her sister and described Faith (PWA) to be such a blessing to their family.

Growing up as a sibling of a PWA, all five participants expressed concerns, more so about the skin than the eyes, of the other sibling with the condition. Grant, for instance, expressed:

> I was worried about the sun because I will go to the internet and read how you can prevent skin cancer. But I never discussed it with him. I did not want to… make him scared or something like that. So, I would go to the internet and check how you prevent skin cancer with people with albinism. I was always worried.

He worried often for his brother, such that he would constantly ask Gabriel (PWA) if he still had access to sunscreen even after Grant moved to Europe and was separated from Gabriel (PWA). Similarly, Donna worried about her brother, David's (PWA) skin. Especially with the hot temperatures in Africa, she stated that David (PWA) was restricted during these unfavourable conditions. He would even bring an umbrella when he was outdoors, but she noticed that the sun would still be a concern to him. The heat would penetrate the umbrella and he would get headaches and feel unwell. Siblings of PWA knew about the challenges of PWA regarding their skin and were hyperaware and concerned of the consequences when their sibling would be out in the sun.

Some siblings without albinism had concerns about being a carrier of the albinism gene. Coral shared:

> It is not that easy, even as an adult now. It means in future, I for instance, can have a child who has albinism. Because I have a sibling, and my parents have one [child with albinism]. It is in the kin relationship.

Although she already had children of her own, she continued to think about the possibility of one day giving birth to a baby with albinism. In the African context, this is a concern not only because the child with albinism will then be subjected to the stigma and discrimination by the community, but also that it may detract potential suitors well before having a child with albinism because the individual has a sibling with albinism. When Donna was asked whether having a sibling with albinism had an impact in her finding a partner or in building relationships, she responded,

> At some point, yeah. Someone here [in the community] said, ‘okay, you’ve got a sibling that have got an albinism’… They would want to branch off. They will say, ‘when you have kids, you will also have children with albinism’. They move away from you like that.

Culturally, finding a partner and getting married is important in Africa, especially for women, but these findings suggest that it is not an easy feat for siblings without albinism and was an aspect that they were concerned about.

Finally, within this theme, accounts of siblings without albinism shared how they felt when they saw their sibling with albinism and other PWA interact with community members. Freya said,

> For me, when I was young, when I heard people talking bad things about [my sister and others with] albinism, I just used to beat them because I was feeling hate. I hear someone [say] bad things about them. I used to feel bad, then I'll beat that person for me to be relieved.

She added, "I feel bad when [persons with albinism] are complaining [about the responses of the community]. I do not feel good because there are many of them out there. They need support. I feel bad because they're in those situations." She described feeling angry and would be on the defensive when people in the community would discriminate against her sister and other PWA, and at the same time, she felt bad knowing what PWA go through. Even during situations when the negative attitudes and behaviours of others were not targeted directly toward them, siblings without albinism seemed to still be affected. They might feel intense emotions and take actions to defend their sibling and other PWA.

Summary of Theme One

To summarize the first theme, the participants all experienced internalized conflicts. PWA, as they have the albinism condition, went through a personal and internalized journey of understanding and accepting their condition. Siblings of PWA shared worries about their sibling with albinism as well as concerns of how albinism impacted their social interactions. Although the majority of my participants shared the same household and have good relationships with each other, the internalization of the condition was experienced separately from each other.

Normalizing Responses: Family Interactions, Responsibilities and Support

A reoccurring thread during the interviews was that participants share how they interacted with each other, with their other siblings, and within their family (parents and extended families) through their day-to-day experiences, their roles and responsibilities at home, and the support they provide to one another. They described their experiences as communal in respect to how they described their family context. PWA and their siblings highlighted the integration of normalcy within the family, which was influenced by the understanding of the family about what albinism is, parenting strategies of their primary guardians (parents, grandparents, aunts), and the culture and values that were important to the family.

Knowledge About Albinism

Of all the dyads, there was a variety of sources from which they learned about albinism. For participants in Dyad A, they learned about the condition at school and from an NGO that was providing them education sponsorship and access to health services. They indicated that their parents knew what albinism was when they were younger because their father worked in an non-governmental organization. Both siblings in Dyad B also learned about albinism at school. As they had access to sunscreen in their local hospital, the whole family, including the aunt with whom they were living when they were younger, were educated about the condition as they would all visit the hospital together. For Dyad C, Carl (PWA) and his parents were educated by extended family members, while Coral took the initiative when she was younger to google what albinism was. David (PWA) in Dyad D learned about albinism when he was already grown, through a famous musician who has albinism and was visible on social media. Donna and her parents did not quite understand what albinism was until David (PWA) was older and joined an albinism organization. They only knew that they needed to protect David's (PWA) skin from the sun.

Dyad E and their parents were not given education about albinism. Only when Edward (PWA) participated in albinism advocacy work did he learn about it and his family learned from him. As for Dyad F, Faith (PWA) learned about albinism at school. Faith (PWA) and Freya speculated that their parents were educated about albinism by a doctor, but the dyad and their other siblings were not involved at that time. Finally, Gabriel (PWA) in Dyad G knew more when people were calling him names and he noticed his physical difference from other children at school. Grant was not given education about albinism; he was just informed by his parents to protect Gabriel's (PWA) skin. Their parents were both teachers and the dyad speculated that their parents knew about the condition. Gabriel (PWA) reflected that perhaps their parents may have had education from their hospital.

All the dyads included in this study mentioned that there was not much discussion in their household about what albinism is, including a genetic explanation about the condition. Belle (PWA) described,

> I don't remember did [mother] ever explain that because it was normal to them. We were just like brothers and sisters. So, I never heard anything more, because I never heard explanations. It was never that she was saying that "you see this one is different, than this one," no. In the house, I feel safe.

It seemed that they did not point out or discuss albinism so that it would feel "normal" at home, that there was no striking difference between the siblings. This was important to recognize as in the next section, knowledge about albinism shaped parenting strategies, how siblings interacted with one another, and how albinism was integrated into their everyday lives.

Parenting Strategies and Impact of Albinism on Parents

Across the dyads, participants shared that they grew up in a way they described as “normal” and were treated as an equal among siblings. By equal, they expressed they did not treat each other differently because one had albinism. Parents also did not show more affection or favouritism over one or the other. Coral said,

> [Our parents] acted to love and accept us giving this spirit because of their strength they just let us grow… With regards to bringing about to promote inclusiveness, equality… The best thing that we [as siblings] can do is to promote it.

The parents in Dyad C provided a space of normalcy in the home, such that Carl (PWA) did not feel any different from his other siblings and his siblings to did not treat him differently. Because of this, Carl (PWA) described his experience with his family as follows:

> With my siblings… it was no different. We together, we sleep on the same mat… I develop quite a relationship with my family. I will say it was a courteous relationship between them… There was no discrimination… The respect was there.

Like Carl (PWA), it was a consensus across the dyads that PWA felt cared for and supported by their parents who encouraged their children to have a “normal” upbringing. There were, however, times when parents recognized the difference in skin complexion. Faith (PWA) stated, “My parents treated me equally with my siblings because they believe it’s just, I don’t have melanin. Me and my siblings are one and that’s what I believe as well.” Their parents acknowledged and verbalized the obvious physical difference but that it was just the difference in the skin colour and PWA were otherwise the same as other children.

Even though parents promoted equality, participants recognized that there were certain things that their parents did differently because there was a family member who had albinism.

This adaptation was integrated in ways that were routine or standardized at home. Anna (PWA) reflected on her childhood experiences with her two other siblings with albinism:

> Sometimes [my parents] have to prevent us from playing with other children just because they are playing under the sun rays. That we may have sunburns. There were a lot of restrictions which they had to give us in order to prevent us from having, especially skin cancer. And also, I can say they had to provide for us a lot in order for us we may not feel different from other children.

Because their parents knew the needs of their children with albinism, parents gave directions to ensure that Anna (PWA) and the rest of her siblings were protected from the sun. She recollected that their mother commissioned their uniforms tailored to have long-sleeves and for them to have custom sewn hats. Adla and Anna (both PWA) described these experiences as customary in their household, with Anna (PWA) adding, “having protective clothing was normalized to us. I mean you should always walk with a long-sleeved shirt, trousers and [to use] wide brimmed hats.” In addition, siblings of PWA like Donna shared instructions provided by their parents specifically to protect PWA, while feeling the routine as normal:

> We just born and we were kids. They were just born that it’s just there. [Her sibling was born to have albinism]. So, the only precautions, I think like when we were growing up… [our parents] would just tell us, ‘okay, you take care of your brothers and take care of your sister. Because don’t move in the sun when you go and play around... Make sure you’re in the shade. And make sure they don’t hurt themself like that. You have seen the skin type. And if you have to bath them when were young, at least they would put something gentle in the water there. So at least to make up that skin to be a bit strong when they were growing up.’ So I think in the home setup, that’s how we were told

> indirectly to say, ‘okay, you need to make sure they don’t move in the sun when you’re playing.’ [But] you can’t restrict them too because [they are] like this [because they have albinism.] You [can’t say], ‘you can’t play with your friends.’ No. So we used to mingle around, but there were those precautions.

Even though the preventative measures were implemented in their family to minimize the risk of skin cancer, and part of the education to protect the skin of PWA involved the siblings without albinism, the household maintained a sense of normalcy where they did not confine PWA but rather attuned to the needs of PWA. As children, they thus were able to function, develop, and interact with others.

There were instances where parents showed “overprotection” toward their child with albinism. Gabriel (PWA) explained that his mother worried about the impact of albinism on him finding a job or entering marriage.

> It was very traumatic for me. My sisters and brothers tried to reason with her. I didn’t understand the reason they gave us, [for why] I stayed home. I didn’t go to the hostel, I schooled from home. She [my mother] became very used to me being around.

He shared that he stayed living at home longer than his other siblings. He remembered the time he was assigned for compulsory year of service to a different province. His mother was upset, and she went to the office at school to contest the assignment because it would be a hot place for Gabriel (PWA) to work. He said that he “may not be able to be fully independent because of albinism.” It seemed that his mother was concerned about him, more so than the rest of his siblings, because he had albinism. But he reasoned with his mother as he needed to work and wished to be independent.

Overall, all participants shared that their parents were very much aware of the skin sensitivity of PWA, but some parents were not given accurate information and therefore unnecessarily altered what families were doing at home. Gabriel (PWA) and Grant described that their mother used to separate food for Gabriel (PWA) from the rest of the family. Grant shared a story when they were children:

> At the beginning, we would see my mom, she would cook food, maybe a stew. And before the end of the stew, and she was still breastfeeding then. And she would take out part of it. So we really did not understand why she was doing that.

Grant later learned that their mother believed if Gabriel (PWA) ate salt, he would develop cracks on his skin. Therefore, while she was breastfeeding Gabriel (PWA), she had set aside food for herself prior to adding salt to what she was cooking. This continued as Gabriel (PWA) grew older:

> We don't give him food because Gabriel (PWA) come to us. He wants to eat from our plates. Like every little brother will do and start to want and take from your meat, want to eat from your rice. And we really didn't understand why he cannot. I think actually that's how we got to know about the reason… although we would give him when my mom is not watching.

Drawing from lay knowledge, she believed a friend who said salt would damage a PWA's skin, and therefore, their mother excluded salt in her own food when she was breastfeeding Gabriel (PWA). She then continued ensuring Gabriel (PWA) avoided salt for years, which the siblings noticed and were confused by. In parallel, Carl (PWA) shared that his mother used to do the same thing but with the reasoning that salt and pepper causes dark spots on the skin. Although parents do this with the utmost great intentions, Carl (PWA) stated, "it's costed a family a lot of resources because you need to prepare different dishes at the same time for the same household and which is not the best.” Inaccurate information such as this impacts the day-to-day of PWA and the entire family, especially if it requires them to unnecessarily use additional resources to ensure that PWA have healthy and “normal looking’ skin.

As indicated above, for the most part, PWA and their siblings all had positive experiences with their parents and the strategies they implemented at home to accommodate the health concerns associated with albinism. One case from this study, however, is different in that family members distanced themselves from the PWA. Edward (PWA), who was raised by his grandparents, shared a story of when he and his siblings visited his mother:

> My mother would tell the neighbours, “This is not my child. It is the son of my elder sister. She has just come here for the holiday.” So, neighbours would ask me some questions, “oh your mother says that she’s not your biological mother, but you look alike”… [At] that time, I was a child, and she would sit me down and say “when they ask you this, you have to respond this.” I used to accept because I was a child, fearing that my mother would shout at me, or I would be beaten, or she would slap me… She did it in a strategic way, because she didn’t just say me alone but including my immediate young brother because she knew that when she would just say me alone, people would suspect her... My mother would tell the neighbours that I’m not her child, together with my young brother probably for fear of being discriminated [against] because of having a child like me… So, I would respond to people to say, “No I am not her son,” because I was young, you see. Because I didn’t know the reason why she said that… maybe she did it in a defensive way because even my young brother who doesn’t have albinism, she said it was

> not her son. So, to me I took it normal. I said probably she has got her own reasons, because it's not me alone but together with my young brother.

Edward's (PWA) mother would not acknowledge him, a person with albinism, as her son and she extended this to the other sibling who does not have albinism to make it more believable. Edward (PWA) feared the consequences if he denied his mother, so he agreed with her statements when in public. By not acknowledging that Edward (PWA) was her son, it seemed that the mother also wanted to be viewed as "normal" by the community. Edward (PWA) reasoned that if his mother had a child with albinism, she would experience discrimination. He also internalized that this was just a normal response by his mother because it was himself and his brother who were not acknowledged by his mother as her children.

Day-to-Day Experiences of a Family Impacted by Albinism

The dyads shared that they participated in typical things that a family in their community would do together. In their everyday, Coral recollected,

> When we were little, we spent most of our time together, like going to the farm with mommy and daddy together. We play around together, we go to the stream to fetch water together and most everything, helping in the house… We mix together to have a little fun.

Coral's family routine involved doing activities together, including those that involved being outdoors where Carl (PWA) would mostly be in the shaded areas. Similarly, Erica shared, "those times whereby you are having family meetings. You are chatting in the house, you are cracking the jokes, you're having different types of stories [sharing] as a family." The siblings and the family of the dyads did many things together, from playing games, sharing stories, and doing chores at home. In this context, the family involved PWA in common daily activities.

As described earlier relating to parenting strategies, there were specific instructions provided by their parents to their children, such as avoiding playing under the sun or to wear protective clothing. PWA and their siblings adhered to what their parents instructed of them. Faith (PWA) explained,

> I do hang around with my siblings. If I’m going outside and it’s sunny, I would make sure, I’ll put on protective clothes. I’ll wear my sunscreen. I’ll put on my lenses. I will have a cap or an umbrella for me to be protected.

Faith (PWA) knew that she needed to wear her glasses and put on sunscreen. These were practices that she was “used” to doing. She further shared,

> My siblings have been [reminding me about sunscreen] a lot of times, more especially when I’m going out with them. [Freya] would make sure I put on sunscreen, and she would carry sunscreen lotion in her bag. “I don’t want you to have sunburn, I’m carrying it for you.” She would carry it minus me knowing of it. At times, I would know that she was carrying. You would just hear her, “[Faith (PWA)], you should first apply sunscreen lotion, you need it.”

For Dyad F, as siblings, they seemed to have adapted to the needs associated with albinism. With guidance from their parents, PWA were found to protect their skin and eyes. Their siblings seemed to also take on the initiative, including bringing sunscreen with them so that it was easily accessible for the other with albinism. Reminding their sibling with albinism about sun protection was routinely incorporated and encouraged in their everyday. Illustrating this “normalized” narrative were Dyad A and Dyad B where more than one sibling had albinism. Adla and Anna (both PWA) shared that they put on sunscreen and protective clothing together. It was helpful because they felt that they were not alone performing these tasks, and this made the situation normal.

Participants also shared how they completed household chores. For some participants, they described that the roles and responsibilities at home were shared. Donna, for instance, described,

> [David (PWA)] used to sweep, [then] sometimes wash the plate. And I would do the washing of clothes. So we used to do, [David (PWA)] used to sweep the house at times. Then I wash the clothes for mom and dad. Yes. It was vice versa. He does it today, then the other day, the other thing, like we are tagged [team].

For most of the dyads, the age, gender, or who had albinism did not affect the allocation of roles and responsibilities. Siblings took turns as to who did certain chores at home. In the African context, it is not uncommon however, where girls and older siblings to perform the household chores. Coral described that she had responsibilities and was taught at a young age:

> Our African traditions and beliefs operate for us to grow, how to become a fully-grown woman. When you are little, they start to teach you some of the house chores, those sorts of things, and how when you grow up to become a woman. So, the next wherever there is an activity for a woman, that is for the elderly ones in the family, they start with those. That’s why by itself when you grow up, you know so many things about womanhood… As little as five, you are taught how to cook, how to perform activities for a woman, like to be a woman when you grew up. They would start to be grooming you for some of the things that a woman needs to know.

Coral recognized that being a woman in the family meant that there were certain activities that were expected to be learned and mastered, such as cooking and cleaning. In some cases, having albinism impacted what chores they did. Faith (PWA) said, “at home I wouldn’t cook. They would not allow me to cook when it was really sunny. They would know that the heat from the sun and the heat from the stove could affect me.” It seemed that if a chore included being out in the sun or being exposed to a source of heat, PWA were exempt from that chore.

Also reflecting on normal family activities, participants mentioned that they celebrated events together as a family. They participated in community events and celebrated with extended families. Bridget (PWA) recollected,

> We do Easter holiday and then Christmas holidays, we are also together. We go to church and then lunch time go to the park. We used to play. So, then our mother would like to make us go out to play after dinner. And then later on we’d have our own dessert.

They celebrated holidays like Easter, Christmas, and New Year’s Day together as a family. Coral said they participated in traditional festivals together where extended family comes to visit, and they would prepare and eat lots of food. It seemed that, within their family, PWA in my study were included during family gatherings, family holidays, and other special occasions. Even as adults now, they would come together for these occasions. Another special occasion that participants mentioned their family celebrated were albinism-related events. David (PWA) mentioned during the interview,

> Yesterday we were celebrating the anniversary dinner celebration at the [albinism] organization. And of course, whenever we are celebrating that, I also invite my family. So those are some of the events which we actually do here to show the spirit of oneness when you are celebrating.

Celebrations on albinism were included as part of the occasions that families participated in as a way to show support to their sibling and to the albinism movement. Faith (PWA) shared that her family celebrates Albinism Awareness Day:

> Most of the times we do celebrate International Albinism Day on the 21st of June. I love how my family come up. Like they'll come celebrate it with me, and that makes me feel special… [Also] they do come to mostly the [albinism organization] when they host a celebration on awareness. My family will come and attend that service with me, and that really makes me happy.

It was evident that events such Albinism Awareness Day were important to PWA, and they appreciated and enjoyed having their family support the cause on albinism and for them to attend these events.

Family Culture and Values

As described earlier, the parents integrated a sense of normalcy in their home so that all the siblings felt the same and equal, which significantly contributed to how they interacted with each other and how they viewed albinism. As all siblings were of Christian faith, some participants described that this was important in their home. Grant shared,

> [Their mother's] belief was God. Everything she does was… being guided by church. And, from a Catholic belief, she taught us that. She made sure we went to church every Sunday. We prayed every day before we go to bed. We would go to church once a week to clean up the church.

The siblings' upbringings were inspired by their faith because they attended church since they were children and continuously drew strength and guidance from God. As evident earlier by Belle and Bridget (both PWA), they internalized what it was like being a person with albinism and would seek God's direction. By going to church, families were able to pray for each other. For example, Donna disclosed that they supported each other spiritually by praying, asking God to keep their "family safe and in good health" and guide them in their journey.

Siblings were taught to maintain the bond they have together: For Dyad G's family, Gabriel (PWA) shared, "mom and dad really did teach us, which has had a lasting impact, is never, never break that family bond no matter what happens." Both siblings in Dyad G stated that, although they now had families of their own and reside in different countries, they never lost contact. They remained to have strong sibling relationships and continued as adults. They connected over the phone almost daily and would even consult their other siblings if one of them did not respond right away. Gabriel (PWA) adored his family:

> The family was always a place to feel at home, there around and that was very positive for me. I never felt treated differently, my parents and family, my siblings. So, I always felt at home when I'm with my family. I mean, we've had our differences, we've had our chores, and, and they will not rest until we resolve it.

He intimated that it did not matter what was going on outside of their family; his family was a stable ground. Grant added to the statements of his brother as well, to say, "[The family] have the brick, the backbone of our success. We always thought we had people behind us, and when we were facing difficulties, we think about them. And it was always a relief." It was evident that they had a close knit family and they were comforted knowing they have a family they can come back to. Their parents highlighted to never lose the connection or bond they shared, regardless of any discordance that occurred. As siblings, it was not uncommon that there may be times they did not agree, and Edward (PWA) gave an explanation:

> You find that in the house… quarrels are there… whereby maybe you are disagreeing on a certain thing. Not [where] you are disrespecting someone who is older than you or maybe you are powering with someone. Actually, that doesn't happen, culturally. But whenever we've got a disagreement in whatsoever, we sit down and resolve it and make [up] as a family.

If two or more members were in a place where they were disagreeing, the most common approach for resolution was for siblings to talk about it. There may be times when the whole family may be involved, especially if resolution does not happen within a day or so. Grant, for example, mentioned that parents may intervene so that they can resolve the problem. Dyads mentioned that it was important to recognize the older sibling, and to be respectful toward them despite having disagreements or quarrels.

Another important value that siblings grew up with was respect. Within Dyad D's family, David (PWA) explained,

> One of the greatest family values that we have been taught or what we have been raised with is respect. Having respect for people despite who they are, where they're coming from, and most of all being humble because you never know what comes... what comes tomorrow. Things change and things are never the same. So, we have been taught always to remain so humble to people and respect each and every person that we meet.

Regardless of the stigma and discrimination David (PWA) and his family faced from the community, siblings of Dyad D were taught to be respectful to every person they meet, no matter who they are and what their circumstances might be.

Finally, parents instilled onto their children the importance of hard work and independence. Faith (PWA) described that she strived for her education, to work hard, and make her mother proud. Although other people may have doubted her capabilities, her family believed in her. With Dyad G’s family, Grant shared that their father instilled “that I [should] work for everything I have. You can’t play tricks or steal things to have anything.” Their family foregrounded honesty and hard work, and specifically that they should not partake in breaking the law or follow “shortcuts” to success. Regarding independence, Belle (PWA) explained: “[Aunt, who was their primary caretaker] taught us to be independent. Not to depend on someone. It’s very important because for us, if you are not independent, is that you are never going to stand up for yourselves.” In their perspective, being independent meant being able to defend themselves against whatever circumstances they may encounter. In this context of independence, Edward (PWA) explained:

> The values of most of the families has to do with how and what I want my siblings or my children to be. In a typical traditional home, they are preparing you for a leadership role in future. They give you responsibility, a task to accomplish. So, at a tender age, you need to start working on solving problems, critical thinking, thinking outside the box. Displaying your maturity, even if you’re not that old. So, that alone is a platform to prepare you and give you a good start.

It seemed that, in their family and community, independence correlated to being self-sufficient. Doing certain things independently, whether that would be chores on their own or facing problems, promoted them to be self-sustaining, self-reliant, and autonomous so that they would be prepared for future responsibilities. Although having a strong bond within the family (intra) was emphasized, their household, and especially their parents, prepared the siblings for what they may experience in the outer world (extra). In the context of albinism where PWA especially experience societal challenges due to their condition, the family household equipped PWA and their siblings to be strong so that they could tackle any obstacles and stand up for themselves.

Family Support

For David (PWA), “when it comes to support… you can’t even count them because there’s just so much” that his siblings and family provided for each other. Just like David (PWA), participants shared many the ways that their families were involved to support them in different aspects of life. Firstly, participants provided advice and inspiration to each other, especially when they both have albinism. Adla (PWA) stated,

> I can say it’s moral support, advice. I can remember after finishing my high school, [Anna (PWA)] was the one who advise me what I could pursue. And also, I can say maybe it’s an encouragement when you see someone out there doing something as I can say that she is my oldest sister and I also have a bigger brother [both have albinism]. When you see them somewhere, it gives you an inspiration of who is doing more in your field. And also, it’s just that for them being there it’s an encouragement that you have someone who you can lean on when something goes wrong.

Adla (PWA) explained that, as she was the youngest, her older siblings gave her guidance about what possible career path and education to take. Adla (PWA) was also encouraged to see her older siblings who have albinism pursuing her goals, giving her motivation to go for hers. Anna (PWA) added, “sometimes [Adla (PWA)] is also a role model… When I look at her, I’m like, ‘okay, this is inspiring. I should be more like her’. We learn from each other.” The inspiration goes both ways; they were encouraged by one another to see what the other was able to achieve.

Second, some siblings reported providing emotional support or were an exemplar to be strong. Belle (PWA) disclosed,

> It was very privilege to have someone like I am with albinism, because… I look up to [Bridget (PWA)] sometimes because she is the stronger one. She is not like the kind of person, a stressing person, an emotional person because I am emotional. Sometimes I look up to her. She says you know, "if she can do like this, why I cannot do that." So, she sometimes is my strong point. She is younger than me but the way she handles the issues, makes me become stronger.

Regardless of who the younger one is, siblings with albinism seemed to view each other as a role model on how to handle challenges and to be strong. They viewed each other as equals, as they both have albinism, and therefore had a mindset of *if they can do it, so can I*. The support can also go both ways; PWA provided emotional support for their sibling. For example, as adults, Faith (PWA) supported Freya when she was pregnant. Freya described that she had great difficulty during her pregnancy, experiencing nausea and vomiting throughout her journey. Faith (PWA) provided her with ample encouragement and was constantly there for Freya.

Thirdly, participants without albinism described positive attribution to having a sibling with the condition. Coral explained that, because Carl had albinism, it encouraged her to research more about albinism through google. She discovered the need to wear sunscreen was not just for PWA but also for her and everyone due to the impact of sun exposure. She knew then that she constantly needed to wear sunscreen, and she proceeded to tell others in the community, especially pregnant women, to protect their skin from the sun. In relation, Freya described that one of the ways that Faith (PWA) assists her was through providing Freya's children sunscreen. Freya's children do not have albinism but knew that they nevertheless needed to wear sunscreen as well. Faith (PWA) was able to obtain sunscreen from a hospital or from an albinism organization.

Fourth, siblings also shared about how they supported one another at school. Freya and their other siblings, for instance, were quite involved in Faith's (PWA) studies when they were younger: "I had difficulty in studying because of my short-sightedness. Most of the time, [my siblings] would try to teach me how to read. If I'm stuck with something, they would help me out, understand it, then until I get it." As she was having vision difficulties, her siblings would assist her to ensure that she could read clearly and understand her schoolwork. This can also go both ways depending on who the older sibling is because in Dyad E, Edward (PWA), as the older brother, shared that he assisted Erica with her schoolwork. It depended on which sibling needed the help or support.

Finally, the most notable support across the dyads that siblings provided to each other and their family was financial assistance. David (PWA) said,

> We came from a very humble background. It was a collective effort from our parents and our siblings to ensure that even if we never had everything, they'll do and make sure that we have all that they could afford to provide for us. Like situations where maybe our parents are financially stressed and there's no way that they could find for them to pay for our fees. Our siblings organize themselves and they contribute whatever they had to just come up with something that would help us with our academics. In regards to books, school bags, uniforms, shoes, they assisted us.

Understandably, the cost of living and other fees like education can be quite expensive. Siblings sensed or observed the financial hardships experienced by their parents. They would assist in paying school fees, transportation, and even other household expenses such as food, clothes, and house payments. Again, this can go both ways between a dyad where one has albinism and one does not, depending on who is older. Edward (PWA), as the older brother, provided financial support for his siblings, including education fees. In relation to albinism, siblings of PWA provided sunscreen and access to other health services. Grant shared,

> At the beginning [Gabriel (PWA)] had problem with concentrating in the school because of his glasses. He was not using glasses until my mom find out that he wasn't seeing well from the back of the classroom, And, we made sure that he had the best glasses. And, we were sending him a lot of [sunscreen] cream that's are very good for his skins. He was lucky to have brothers who could do that because many many people in the same situation in [Africa] who couldn't have that [sun]block as he did… And then he came to visit us here in [Europe]. He was [living] in [Africa still]. We took him to different doctors to check his skin. We went to optician to check his eyes, and he got glasses from here. And we made sure that he got a complete medical checkup here. We try to spoil him sometimes.

Grant and their older brother who moved to Europe supported Gabriel (PWA) in obtaining the necessary health services such as sunscreen, eyeglasses, skin check-up, as well as a complete medical checkup. Gabriel (PWA) reflected, "when [his older brothers] left home [from Africa], it was like they told themselves, 'Well, I've not gone to [Europe] for myself. I've actually gone so that I can care for my family back home." Despite his brothers going to Europe to find better opportunities for themselves, they still looked back on their family and ensured that each family member was supported and cared for. In their case, they incorporated the needs of Gabriel as a person with albinism to support him.

Access to Health and Social Services for the Dyads

Of the seven dyads, only Dyads B and F had access to sunscreen at their local hospital while they were growing up (albeit this access was not consistent or reliable). Belle (PWA) recollected that her mother would buy sunscreen for her and Bridget (PWA). As described above, family (parents and/or siblings) were often involved in purchasing sunscreen or eyeglasses at some point and this was the case for Dyads A, B, D, F, and G. Dyads A, D and F were also able to access sunscreen through an albinism organization if the organization had supplies, which was not always, as these participants worked for albinism organizations. As for peer support, Dyad A and David (PWA) said that they had access to peer support from albinism organizations. Regarding siblings without albinism, they were not provided with any resources whether that was genetic counselling to obtain education about albinism or any sort of peer support and counselling.

Summary of Theme Two

It was apparent within this theme just how integrated albinism was within the siblings' and families' day-to-day lives. Although they normalized family activities together and attended shared events, they made accommodations to ensure not only that PWA were supported to address their health concerns but also that the family created a loving and caring environment at home, protected and safe from what they otherwise experienced in their community.

Stigmatizing Experiences: Community Context

Participants, both those with albinism and those who are siblings of PWA, were well aware of and shared with me the beliefs associated with albinism in their community. They described the stigma and discrimination they experienced, including times when PWA were at school. They described their safety and security concerns due to the recent reports of violence against PWA.

Beliefs About Albinism in the Community

All participants enumerated various beliefs about albinism in their community, emphasizing that most people did not have a genetic understanding of what albinism is. According to Carol, people believed that the condition is contagious, that it is a "sickness." She said, "maybe when you come closer to the person, you're also going to be like the person. Or when you eat together with him, you're going to be like him." People in Dyad C's community believed that if one had physical contact with a person with albinism or touched anything PWA had handled, the condition was going to pass on to them. Faith (PWA) also shared the same beliefs in her community where she heard people around her say "no, if I touch her, I'll be like her." Participants also reported the community held belief that if a pregnant woman meets or even just sets eyes on a person with albinism, she will then give birth to a baby with albinism. Freya witnessed people spitting on PWA or onto the insides of their own shirts to counter that belief so that they would not have a child with albinism.

Participants also shared supernatural beliefs associated with albinism. For instance, Coral described some people thought that "it's a curse to have such a child." Therefore, they would stay away or avoid PWA. Moreover, David (PWA) and Donna shared that people around them believed that PWA do not die. Instead, they just simply disappear or vanish. They both shared a story of when they had a funeral for their youngest sibling who had albinism and had died young. Donna remembered, "There were a lot of people who came for burial at the graveyard because they wanted to verify to say, 'okay, these people [with albinism] don't die.'" They heard people talking the said belief during the viewing, burial, and throughout the funeral event. People in their community came to verify that Dyad D and their family, indeed, buried their sibling who had albinism, and that she did not just disappear.

The most common and disturbing for PWA and their siblings was the belief that the body parts of PWA were associated with success and thus were sought after for ritual purposes. Edward (PWA) explained,

> There is a belief that the body parts of persons with albinism can make someone rich… Some [PWA] are being killed, some of them are left disabled because of that particular belief.

They also heard of this from the news in which PWA were being attacked because of this belief. PWA's body parts were said to be used for ritual purposes.[1] Edward (PWA) added that there were people who believed that when one sleeps with a man or woman with albinism, they would be cured for HIV or AIDS. For Faith (PWA), because of these collective beliefs, people were afraid of her, and some would directly tell her about these beliefs while in public.

Stigma and Discrimination

All PWA in this study reported experiencing stigma and discrimination from their community. Most prominently, participants described their interaction with the community by directly using the terms "stigma," "discrimination," and "exclusion." When asked for more details, some participants with albinism recounted times when they were questioned about their parentage. Carl (PWA) was often asked: "Are truly, both of you, all of you [siblings], from the same father or same mother?" Some people were doubting whether he was related to his other family members, that perhaps he was born from parents with the same-coloured skin as Card (PWA) had. The siblings without the condition were asked the same questions. Edward (PWA) shared he heard from his siblings' friends when they asked questions such as: "how come, is he

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[1] Participants in this study did not use the language of witchcraft to describe the attacks on PWA for their body parts. However, harmful witchcraft-related practices have often been associated with the reported violence against PWA (Reimer-Kirkham et al., 2022).

really your brother?" It seemed that because people did not know what albinism was, they attributed the difference in skin colour to PWA not having blood relations with their family members with darker skin complexions. In the context of the physical difference of PWA, Anna (PWA) explained, "for the rest of the community, I can say that they have issues accepting the difference [in skin colour]. Especially when it's so striking, when you look white and the majority [of] people that are around are black." Their skin colour stood out among community members, and therefore, PWA received a lot of questions and attention. As people were unaware about what albinism was, they were trying to find an explanation to their skin colour, especially noticing that PWA were quite obviously physically different from their family.

Some people also wondered about the capabilities of PWA. For example, Adla (PWA) shared, "Each and every person walks down you, thinking maybe there is something that you can't do and she or he can do." It seemed that people believed that albinism causes physical weakness or limitation unrelated to the visual impairment or skin sensitivity to the sun. When they were children, some individuals questioned whether they could participate in certain activities. When he was young, Carl (PWA) remembered when he engaged with neighbours his age to play football, they at first did not want him to join and expressed anger that he approached them. But then, they were surprised that he was able to chase the ball and actively play. For him, Carl's (PWA) capabilities were doubted not just in terms of playing but with various activities, including his abilities to perform well academically. It seemed that PWA were seen as inferior and, through actions, PWA intervened by showing people that they indeed were capable.

Overall, participants described that they were "treated differently" or would hear "bad things" about them, sharing that it was challenging growing up with albinism. They often heard people, both children and adults, call them various names such as "*ofrri*" (Ghana), "*swine*"

(South Africa), “*zeruzeru*” (Tanzania), and “*mzungu*” (Zambia). The terms were not just for PWA but may also be referred to the whole family. Carol said, “they use the plural for all of us. It plays albino for all of you,” indicating that siblings and the family were called the same derogatory names. They experienced stigma and discrimination in various places. Bridget (PWA) shared that this even occurred at church:

> I was trying to praise God singing. I was trying to make myself happy. But someone who's staying next to my sight, he or she is going to undermine me because of the skin of my color. That was very painful to me and my family because sometimes I wake up happy, telling myself, “I'm going to church, I'm going to praise God doing like this” … [but] someone takes that happiness.

Bridget (PWA) went to church with a happy and positive attitude with her family with the intention to partake in the church service, but she felt that her day, as well as her family’s, was ruined because of such attitudes and behaviour from her community. Growing up, participants indicated that they have grown accustomed to it or that they have gotten “numbed” because these are situations that occurred frequently.

Many of the negative experiences that PWA and their siblings recounted were prominently worse during their childhood than as adults now. In some cases, it was more challenging for the first born with albinism than the younger siblings, when more than one has albinism. Adla (PWA) and Anna (PWA), for example, said that everyone was looking at Anna (PWA) being the first born. Because she was the eldest, people in the community were being exposed to someone with albinism. For Adla (PWA) being the youngest, her experience was better because of the increased sensitization on albinism in recent years:

> Nowadays, I think the awareness has grown. And also, the people with albinism [are] on social media like Instagram or on the television. People have gotten used to [albinism]. So, the stigma has decreased, although it's there to a lesser extent.

PWA indicated that things have started to change in their community because of the albinism campaigns and the presence of PWA on social media. There were musicians, for example, who were vocal about the various issues associated with albinism and often appeared on television to sensitize people. As mentioned, most PWA in this study worked with an albinism organization and have started to see the community responding positively to the albinism advocacy. According to Faith (PWA), people would say things like "we never knew about albinism" or "we thought the myths and misconceptions we've been hearing were true, not knowing that we are all one." Adla (PWA) also added that there were now members in the community who would defend PWA when others were calling them names or treating them differently.

Education and Experiences at School

As described in the previous section, some PWA gained the genetic explanation about albinism at school. But long before that, when they were too young to have these topics taught to them (i.e., during primary school), PWA noticed their unique physical attributes through the reactions of other students. Gabriel (PWA) remembered his first experience when he started primary school:

> I got to school, I think I was being shown my class and others were already seated and when I walked in, and the "awe" and the mocking of words was very obvious. And some laughing and that's when really at that very young age, I for the first time was, "what's going on here?"

As their family may not often acknowledge or mention their differences in skin colour at home, PWA eventually realized or discovered such differences when they attended school where they would be subjected to mockery, bullying and name-calling. David (PWA) shared the same experience and explained that he had major challenges due to “stigma from kids… segregation and the exclusion in the certain area that we were, just going to play around at school.” At a young age, PWA already experienced stigma and discrimination and would learn they had a difference in skin colour through their interaction with other children at school.

PWA expressed difficulties at school because of their vision and skin care. All PWA in this study were not provided with assistive devices or given any type of special consideration for their visual impairment and sun sensitivity by the school. Instead, PWA took the initiative to sit in the front row of the class to be closer to the board. This strategy, however, was often not sufficient. Anna (PWA) shared she was not able to take notes because they were written on the board. She mentioned, “for the test that were done by the teachers writings on the board, I failed most of them because obviously I wouldn’t see what was written.” Even though PWA sat in the front row, there were times that they could not see the writings on the board. Anna (PWA) often failed tests that were written on the board, but she would do well during midterm and final exams because those were given with questions already written on the paper. The teachers of my participants did not know what albinism was. Gabriel (PWA) said that his teacher got “pissed” at him because he did not take notes during class. Gabriel (PWA) and Grant also described that there were no exceptions when students needed to be outdoors. They both remembered a time when the punishment for students was to stand outside in the sun. In secondary school, Gabriel (PWA) had to stand outside for six hours which resulted in sunburn and the development of spots on his skin. Teachers in schools did not know what albinism was and they did not make any arrangements to support their vision and protect their skin.

Some participants in my study indicated that their experiences at school got better when they met a friend who accepted them. A friend of Belle's (PWA), for example, would always be by her side and defended her from the other children who were calling her names. The friend also gave her encouragement to accept herself: "she told me, how I must understand myself. I must be proud of myself. And if I'm having a problem, I must not keep it for myself… [and] that people must understand, and I must make them to understand." It seemed that Belle (PWA), when at school, drew strength from her friend, whom she is still connected with to this day. For Anna (PWA), she stated she "hated school" but when she reached secondary school, she met a friend who liked her just the way she was. She commented, "peer support really helped. Having people around you that show you that it's okay to be you." Being different among peers was challenging but having even just one friend made a big difference for PWA and could shift their whole school experience to be of a more positive one.

The Responses of Persons with Albinism and Their Siblings to the Community

PWA in my study shared that they defended themselves against people who discriminated against them, even young children. Bridget (PWA) shared that when she was young, she spoke up to the parents of other children who were calling her names or treating her badly. She advocated for herself saying, "I'm also a person like them." She approached other children to have them touch her, showing that she was not a ghost. As children, PWA stood up for themselves emphasizing that they were human and did not deserve to be treated badly. Such actions illustrated how PWA would demystify the beliefs about albinism. Edward (PWA) similarly shared that he remained visible in his community, participated in activities like concerts, and studied hard at school where he achieved a scholarship. PWA in this study proved to the people in their community that they were human and capable, and they took actions to debunk the misconceptions about albinism. As grown adults, PWA reported that they actively educate people about albinism. Faith (PWA) shared, "I sensitize people... I teach people about albinism for them to understand the kind of person I am." PWA indicated that the awareness raising they conducted had influenced the social change they were presently seeing in their communities.

Siblings of PWA were also found to have responded to the community. Freya and Faith (PWA) shared that Freya organized and gathered a group of people in their community and said:

> I've heard a lot of people say a lot of things about my sister. I'm here to answer each of the questions you've got. You ask me and I'll educate you more about my sister since you think she's a burden to us but to us she's not a burden, she's also a human like you are.

Because of the various beliefs associated with albinism that contributed to her sister being stigmatized in the community, Freya took it upon herself to bring people together, answer their questions about albinism, and emphasize that Faith (PWA) is a human being and is not in any way putting hardships onto their family or community. Faith (PWA) did not ask for her sibling to do this and thought it was a great gesture. Siblings of PWA knew of the struggles of being a person with albinism, and wished they could support other PWA. Freya said,

> When I was growing up, I was like, if God bless me with money, I would like to just open an orphanage or something for albinism, because most of them, they are in villages. There are so many [persons with] albinism but they're lacking support.

It seemed that siblings had an increased sensitivity to what PWA were going through and had the urge to help them. Coral and Carl (PWA) also shared that Coral educated people about albinism in their community. Coral felt bad about what Carl (PWA) and others with albinism were going through, saying,

> I try my possible best with the little knowledge I have to educate people about the condition, that it's just a disorder from birth. So, it's not a sickness or a transferrable disease that you can have when you come closer to them. Wherever there is a crowd or there is a gathering, that [education] makes him to feel accepted.

She educated people on multiple occasions to enable understanding of the condition and acceptance of Carl (PWA) by the community. Carl (PWA) appreciated his sister and that she was engaged with this response, saying "thank God for her." Coral's engagement in educating their community was significant for Carl (PWA). Despite the activism of PWA and their siblings however, they shared safety and security concerns due to the beliefs associated with albinism.

Safety and Security Concerns

Participants shared varying levels of concerns regarding safety and security which depended on the proximity of reported attacks against PWA. Dyad A, in particular, lived in an area where there were active killings and numerous attacks against PWA when they were growing up. Their parents, however did not show fear when they interacted with their children, but simply deemed that their children (all with albinism) may be in "immense danger." Therefore, Adla and Anna (both PWA) went to boarding school. When they were young, they worried for their safety because the attacks were escalating in their country. Their safety remained a source of concern for them to this day, as they recently learned of an attack on PWA in another province. For the other dyads, they also heard of the atrocities against PWA, but the cases did not occur around their area. Thus, they did not feel as threatened. Edward (PWA) explained,

> We don’t experience attacks on persons with albinism because this is an area where people, they seem to be acquainted with our albinism knowledge. In our community where we stay, we have never recorded any attack on albinism, because it’s an urban area. Attacks here in [XX country], they concentrate in rural areas specifically in those areas which are bordering the other country…They lack information about albinism [in rural areas].

As he worked closely with an albinism organization, he took part in raising awareness about albinism in his community. He also recognized that people in urban areas were updated on news and other relevant information through the radio, television, and cellphones with access to social media. He theorized that the killings were in rural areas and were related to organized crimes where perpetrators would first observe PWA or connect with someone close to PWA and their families before attacking. Edward (PWA) concluded, “I cannot fear in any way so long as I’m always alert, security wise. Because these attacks, they actually involve someone who can actually betray you.” Apart from Dyad A, PWA in this study knew about the attacks against PWA and were concerned for their own safety, but this concern was not described as drastic because the attacks did not happen in their area. They, however, did take precautions such as going outside only in the afternoons, according to Faith (PWA).

In this study, siblings without albinism expressed worry in regard to safety and security not only for their sibling with albinism but also impacted the safety of their entire family. These concerns resulted in precautions undertaken by the entire family. Carol said that she heard of the attacks against PWA when she was growing up and she and her family were worried for Carl (PWA): “We’re scared for him going out alone, especially in the night. So we don’t allow him alone to walk in the night. We always make sure he’s being accompanied by someone when going out." These were the precautions that their family would make to ensure Carl (PWA) was safe. Similarly, Donna explained that their family were "partially safe." She and her family also heard about the killings of PWA on the news. She stated,

> You fear how we are safe there, moving at night or because the time in other areas where they've been attacked during daytime. Yes, you worry about what might happen. It has been a concern for us because we might be sleeping, then they come through [the house] to attack us because they attack even where they know that there are [other] people there [at home]. Also, they are those people [the attackers] that are close to you… Who is with us and who is not with us? Others might just be with us because they're family members: they're close friends, they're neighbors, but you don't know what is in their mind. They might select us. They might sell us out… that [we are] open and easy, "we can go there and attack them."

Donna's concern extended to the entire family. Because they had a family member with albinism living with them, their house could be a target for attacks; individuals with bad intentions could come at any time during the day or night. She also worried about who the family would be engaging with, whether they were simply befriending them, or would there be an ulterior motive where their information would be given to those who might want to attack David (PWA) and her family.

Summary of Theme Three

In this section, I presented participants' insights about the various and still existing beliefs associated with albinism in their community. Although the responses of the community were reported to have improved, PWA, their siblings, and the family continued to experience stigma and discrimination. This led PWA and their siblings to participate in raising awareness about albinism in their community. Due to the reported attacks however, PWA and their siblings shared continued concerns for their family's safety and security.

Encompassing Support: Needs of Families Impacted by Albinism

Participants in this study shared what their needs were and provided recommendations for how to support siblings and families impacted by albinism. Their recommendations include (1) education and acceptance of albinism among the family; (2) financial support and access to health and social services for the family; and (3) raise awareness on albinism in the community.

Education and Acceptance of Albinism with the Family

The most prominent shared recommendation that participants deemed important in supporting families impacted by albinism was providing the whole family with education about the condition. According to Adla (PWA), educating parents at the time of birth is critical to allow them to understand what albinism is, providing them with the information they need to take care of their child. A big part of the experience of PWA growing up was their sensitivity to the sun (with the concern to their increased risk of skin cancer) and their visual impairment. Parents, especially the mother, should be able to leave the hospital "confident on how he or she can take care of his or her child with albinism." They needed to be equipped with education about protecting the child's skin and providing them with prescription eyeglasses. Gabriel (PWA) specifically drew attention to the role of healthcare providers in educating parents and the siblings:

> I think it's very crucial that if a family has a baby with albinism, the specific healthcare providers that provide where that baby was born, the hospital where that baby was delivered, has a very important duty of educating, not just the parents of that child but the family. Because I think that's where it all begins, you know. Many families go home with

> this child they don't understand. They don't understand… it can easily bring about confusion. If you don't have any idea what has happened, you may end up assimilating the general beliefs and psychological understanding already circulating and what is more worrisome is that the child with albinism will grow up to think of themselves as something different in that same understanding because there was no other, you know…healthcare providers have that primary responsibility… they need to really take it seriously of not just educating the mother who has birthed that child, but also the father, the siblings as well.

According to Gabriel (PWA), all family members should be educated about albinism to prepare them for when the child comes home. This education would help the family to not resort to myths or other inaccurate information about the condition. Although siblings of PWA in this study were relatively young to be provided with information about albinism at the time of birth of their brother or sister with albinism, they indicated that they too would like to be given education about the condition. Erica described, "I'm not knowledgeable about PWA… I need to be acquainted [with the condition]." As with other dyads in this study, Erica's family did not discuss what albinism was at home. Thus, she only learned about what albinism was when she was grown. She received the information from her brother, Edward (PWA), when he started appearing on television, participating in interviews to sensitize the society about albinism. Siblings of PWA in this study specified that this information would not only support them in understanding albinism but would also equip them so that they can educate the community.

Participants also shared that in addition to education about albinism was the need to show acceptance of PWA within the family. Carl (PWA) explained,

> I always say that discrimination or negative impacts based on one's condition starts from home. If you do not have the basis or the good support or the family support, that is where the endangering of life and the discrimination that we [are] talking about starts from. If the immediate family do not recognize that we are born [the same], but with different complexion, no amount of support or actual affection… That is where the disparities or discrimination or the challenges come from. Things will not be normal or alright for families.

Carl (PWA) emphasized that families should understand that although PWA have a different skin complexion and require vision and skin care, they are born the same. If PWA experience stigma and discrimination at home, it will bring further disparities for the family and, particularly, for PWA. Acceptance of PWA must start from home and Anna (PWA) stated that this should start at a young age:

> Because when we are young, that is when the situation is more challenging. As we grow to adulthood, we become numb to the situation… most of us grow up with issues that we have just covered up. So, we have a lot of mental health issues, anger issues because of the situations that we have grown up with at a young age. But if the support system, for those siblings to just help them normalize the condition. That is really helpful in terms of building their self-esteem, self-confidence, knowing that in having a positive outlook on things and knowing that despite being this way, I can accomplish it all.

As described in the earlier sections, PWA experienced many challenges, especially when they were interacting with the community. Thus, they internalized the situation and might develop mental health issues that they often did not share with people around them. Anna (PWA) stated that having a strong family support system is key to help PWA realize their value, validate the emotions that they may be feeling, and encourage them to pursue their goals and develop into their full capacities.

Financial Support and Access to Health and Social Services

The dyads in this study described the many ways they provided financial support and access to health and social services for each other, indicating that they needed external (i.e., government, community, or NGO) support in this regard. They shared that when they were growing up, they were aware of the financial difficulties that their parents were experiencing to ensure basic needs such as food and housing. Belle (PWA) and Bridget's (PWA) mother went to a different province to work, and they had to ensure that the money their mother sent them would last for as long as possible. Belle (PWA) described that she and her siblings sometimes baked cakes to sell to their neighbours so they could earn money. When they started going to school, the expenses increased, especially when they reached post-secondary education. David (PWA) was in university at the time of the interview and shared,

> For me because I'm in school, I need resources. There are so many things that are needed in school [that] need money. You need to do assignments; you need to get some stationary. Sometimes the weather is not allowing you to [walk] to school. You need to secure something for transport, food, accommodation.

Growing up and until now, David's (PWA) family struggled financially. This struggle was heightened further as he was in post-secondary education and relied on his parents and siblings for tuition, books, food, accommodations, and other basic needs. He and other participants in this study emphasized that financial support is important to aide families.

Having a PWA in the family also meant that parents had to spare financial resources to buy sunscreen. Donna explained, "It's a bit of a financial stress on us because we need to get sunscreen cream that can help him to move in the sun. And they're really, really expensive. It's difficult for us even to acquire just one bottle." Because one sibling needed sunscreen and their family was financially limited, it was described as an issue for the whole family. PWA in this study stated they needed access to sunscreen and prescription lenses as well as access to skin and vision doctors (i.e., dermatologists, ophthalmologists, opticians). Only Dyads B and F had access to sunscreen through their hospital, while PWA in Dyads A and D obtained them from albinism organizations. Faith (PWA) and Freya's family also had financial hardships. Freya explained, "even at home we won't eat, as long as they buy lotion for her. If it means to eat just vegetables, we would eat. As long as her body looks nice, her skin. We protect her a lot." At times, they would limit the type of food they ate so that they could buy sunscreen for Faith (PWA). The families of PWA had made skin protection a priority.

Having a sibling with albinism greatly impacted the family, including how they viewed others with albinism. Grant explained,

> Personally, it is just if I know people are aware on how to handle people with albinism, how to support them, that's very helpful to me. Because we have learned, I've learned a lot. And I just hope all the time, or maybe sometimes I see people with albinism, and the first thing that comes into my mind is, I hope he or she's getting the support we give to [Gabriel (PWA)].

Grant shared that he and his family learned a lot about caring for a person with albinism through his experiences with his brother. He recognized that the support that he and his family provided was instrumental for Gabriel (PWA). Grant's statement indicated that if PWA were well supported, families impacted by albinism would also be supported. The dyads in this study recognized that their experiences are unique contrary to many PWA who did not have the support that they had. The dyads also highlighted that government needs to address the lack of access to health and social services for PWA as this will benefit the whole family.

Siblings of PWA in this study were not provided with any access to social services or mental health resources. When asked if such resources would be helpful for siblings of persons with albinism, participants without albinism responded, “definitely” (Donna) and “yes, that would be helpful very much” (Freya).

Sensitize the Community About Albinism

The spread of information to demystify and debunk the myths associated with albinism has vastly improved the day-to-day experiences of persons with albinism. Adla (PWA) described her experiences when in public now:

> Maybe somebody does something that acts like stigma. But without you defending yourself, another person comes along again and says, “no.” Maybe they say, “you are not supposed to do that thing… because she’s the same as you and me.” So, instead of you defending yourself, someone in the community, one passerby defends you, from another person.

Being in an area where there were people who finally understood what albinism was meant that there were less instances in which PWA experienced stigma and discrimination. When people would display stigma or say or do something unpleasant as Adla (PWA) described, there may now be people willing to defend and even educate others about albinism. PWA in this study shared that raising awareness about albinism among community members was important to support siblings and families impacted by albinism. Edward said, “We have to continue disseminating the information because the more we disseminate the information, the more people learn. We’re disseminating the information to the general public.” He emphasized that education in the community was crucial because of the challenges that PWA in the community experienced in relation to beliefs about albinism.

Summary of Theme Four

In this final theme, the dyads shared recommendations about the many ways to support families impacted by albinism. It included ensuring that the family, both parents and siblings, are provided with education about albinism especially at the time of birth. Participants emphasized the need for having a strong family support system and encouraging acceptance at home. They also stressed the importance of supporting the family through financial assistance and access to health and social services, as well as the need to educate the community about albinism.

Chapter Four Summary

It was normal to them [my family]. We were just like brothers and sisters… In the house, I feel safe.

- Belle (PWA)

In this chapter, I outlined the findings from my interviews with seven dyads through dyadic thematic analysis. The themes presented in this chapter are complex and interconnected and participants were significantly influenced by societal responses and understandings of albinism. PWA and their siblings faced psychological and psychosocial struggles that they often kept to themselves. PWA had underwent a journey towards acceptance and understanding their condition. Although the families represented by the dyads in this study did not discuss what albinism was at home, the majority had a basic understanding of how to care for a PWA, in which they integrated skin and vision care in a way that normalized the practices of wearing eyeglasses, sunscreen, hats, and protective clothing. The families included PWA in their everyday lives, from sharing household chores and childhood play when they were younger to attending celebratory events together as grown adults. PWA and their siblings shared that they experienced stigma and discrimination growing up due to the still present and prominent cultural and spiritual beliefs attributed to albinism. These beliefs, in addition to the reported attacks and killings of PWA in Africa, heightened their safety and security concerns for their family. Many of their recommendations to support a family impacted by albinism involved the need to provide health and social services and educate the family as well as the community about albinism to improve the experiences of PWA and their siblings. The direction provided by participants was to support PWA in order to address the challenges experienced by the family.

CHAPTER FIVE: DISCUSSION

In this chapter I discuss the findings of this thesis. The purpose of this study was to explore the experiences of siblings impacted by albinism in Africa. The objectives were:

1. To examine the family dynamics of having a sibling with albinism, including their social, political, economic, and historical contexts,
2. To analyze strengths and challenges between siblings (intra-family) and in the community (extra-family) in relation to albinism, and
3. To explore implications for healthcare providers to enhance a family-centred approach that integrates sibling support as part of the healthcare for families affected by albinism.

To show how the findings address these objectives, I first present a synopsis of my findings in relation to the three objectives and introduce two frameworks developed to visualize the results of my data analysis. Then, I deepen my interpretation of the experiences of PWA, their siblings and the family through the lens of disability, family theory, social determinants of health, and human rights. As explained in my literature review in Chapter Two, this study is the first to address the experiences of siblings impacted by albinism in Africa, and thus the entirety of the study represents a contribution to the existing evidence on albinism. Without having other studies on this topic, I have had to draw more generally and widely on literatures to interpret the study findings.

Synopsis of Findings in Relation to Study Objectives

I interviewed seven dyads (fourteen participants) from Africa. Interestingly, rather than simply expressing their experiences in either positive or negative terms, the dyads revealed more complex perspectives as PWA or as siblings of PWA. The participants included in this study are unique in many ways. Growing up, they witnessed the time when societal views were distinctly and strongly influenced by erroneous cultural and spiritual beliefs associated with albinism. Participants came from five countries (Ghana, Nigeria, South Africa, Tanzania, Zambia) where the negative perceptions and acts of violence on PWA may be less or more prevalent in demographics, influencing the gravity of concerns for attacks and feeling unsafe. Although these beliefs continued to exist as they were older, the dyads were witnessing the start of social change as they all grew up during the albinism human rights movement (see the accomplishments of the UN Independent Expert thus far: UNGA, 2020c). It was evident that the challenges they experienced growing up significantly influenced who they grew up to be as the PWA included in my study were involved in promoting the rights of PWA in a variety of ways. PWA had to undergo a process of understanding what albinism was because of the psychological and psychosocial factors fostered by stigma and discrimination. The community's attitudes were experienced by their siblings by association because they had a brother or sister with albinism. Although PWA in this study and their siblings grew up happy and supported, it was nevertheless challenging to grow up with albinism, mainly when they left the safe and comfortable environment of their home and entered the scrutiny of the society. Both PWA and siblings shared that they experienced name-calling and exclusion because of albinism. They enumerated the persistent beliefs about albinism and how that impacted their safety.

Another way that these dyads are unique is that they shared mostly positive stories on how their family lived with albinism, showing that their families are great lessons (or teachers) to learn from. As they had a basic understanding of the condition and recognized its health implications, PWA, as well as their parents and siblings, ensured that PWA were protected from the sun. Often, the family were the primary resource in accessing sunscreen, protective clothing, and eyeglasses. Despite the adaptions that the family made in their family life, they maintained a sense of normalcy in their home so that PWA did not feel that they were any different. Thus, the findings revealed that family functions as an important support system for PWA. This pointed toward the framework shown below (Figure 4), where PWA were significantly impacted by their SDoH. Each pillar represents a key determinant to one's health outcomes and they need to maintain stability in order to build on, for one to not only have good health and well-being, but to flourish and thrive. Such flourishing is marked by strength, acceptance, ambition, self-confidence, and resilience. The findings of my study indicated that family support was embedded in each key determinant, liked to *steel rebar*[2] for PWA to have access to these essential elements. Families provided the strength and support—equivalent to tensile strength—which created the conditions to enhance the capacities of PWA.

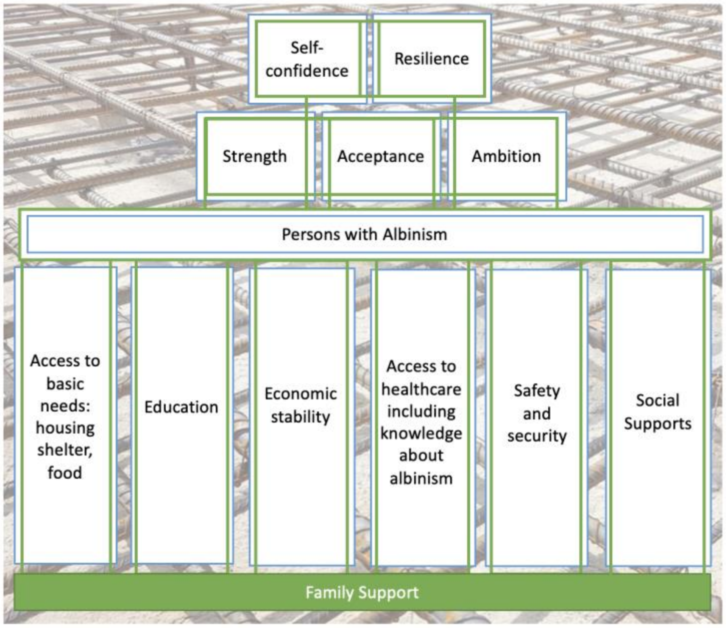

Figure 4: Family as a Social Determinant of Health

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[2] In this study, I use a *steel rebar* as a metaphor to represent how the family plays an important role for my participants. A steel rebar is typically used to reinforce concrete. Its main purpose is to increase the tensile strength of concrete to resist cracking and breaking (Alto Steel, n.d.). Concrete is weak under very strong compression, thus steel rebars are inserted. With a greater tensile strength, concrete can better resist breaking under tension. Family is the steel rebar, reinforcing stability and strength in the midst of challenges faced by PWA. Families gave the stability for PWA to flourish and thrive.

The findings also suggested that when PWA were not able to access key determinants, the whole family was impacted. Family members took on the burden to address PWA's concerns and needs and they were equally impacted by the SDoH (see Figure 5 below), especially where they too experienced discrimination and exclusion by association. Families, as a unit, faced challenges when there was no access to healthcare, education, and support for living expenses. I also foreground the connection between SDoH and human rights. Many key components of the SDoH such as access to nutritious food, adequate housing, clean water, safe environment, and education are human rights that everyone is entitled to (Chapman, 2010). Among these, the right to life and security is a fundamental right of PWA as with any other individual. Yet the reality for many PWA and their family is a life of disproportionate challenges coupled with fear and insecurity.

Figure 5: Social Determinants of Health Impacts the Family

Addressing the first objective of my thesis on examining the family dynamics of having a sibling with albinism, the dyads expressed their family to be close and described their relationship as communal and “normal.” The dyads and their families were significantly influenced by their social contexts, given that perceptions and beliefs about albinism remained a big contributor on how they were able to live, work, and play. Although in most cases their families had a basic scientific understanding of what albinism was, some parents believed in or were affected by the cultural beliefs, which then reflected on how they responded and parented their child(ren) with albinism. For example, the family had a heightened sense of awareness of the safety of the siblings because of the reported attacks against PWA, even though there was no violence reported near their area (except for Dyad A). Likewise, without diving too far into the political and historical structures of the five countries represented in my thesis (which are beyond this thesis’ scope), the dyads’ experiences were shaped by their political and economic contexts whereby the lack of consistent health and socioeconomic support placed a disproportionate burden on the whole family. All their parents worked hard to provide for their family, yet the participants shared that they continued to face challenges to ensure that the necessary daily needs were met. Siblings often had to step up to support the whole family as well.

For the second objective in analyzing strengths and challenges between siblings (intra-family) and in the community (extra-family) in relation to albinism, I highlight the crucial role that family played in the growth and development of PWA and their siblings. Although they did not discuss the topic of albinism in their homes, the dyads and their family integrated a sense of normalcy, promoted acceptance, and encouraged equality among the siblings while considering the health needs of their family member with albinism. They walked alongside each other in various stages of life, always being their constant. They were raised to work hard and be independent, leading to each participant pursuing their personal goals. In addition to the financial difficulties that the dyads shared, the main challenges faced by PWA, siblings, and their families concerning albinism were due to the perceptions and responses of the community, whether that was at school, their neighbourhood, or in their communities, in general. Thus, PWA and siblings had mental and emotional concerns, including worry for their safety and security.

The last objective was to explore implications for healthcare providers to enhance a family-centred approach that integrates sibling support as part of the healthcare for families affected by albinism. This study showed that family was paramount in supporting the health and well-being of PWA and their siblings, given that their lives were so interconnected even as adults where they have their own families and careers. They continued to support each other in various capacities (i.e., emotional, social, and financial support) and always remained connected, being present during important family activities and gatherings. When they needed assistance, they turned to their families. Therefore, it is important to broaden our perspective in integrating a family-centred approach, recognizing that family circumstances, dynamics, and support play a critical role in the lives of PWA. Especially when protecting the skin and providing for the vision concerns, their siblings and family were significantly involved. Likewise, my study revealed that PWA needed consistent access to sunscreen, eyeglasses, and other assistive devices, including at school, as well as mental health counselling. Family members, such as siblings, also needed support and specific interventions that address their concerns, like access to mental health counseling and genetic counseling. In the remainder of this discussion chapter, to deepen my interpretation of the findings, I re-read the findings through four lenses: those of disability rights, family theory, SDoH, and human rights.

Disability Studies: Assimilating Albinism in the Family

Albinism is increasingly situated in the discussion of disability due to the health and social implication of the condition that heightens their vulnerability (Brocco, 2015; Mswela, 2018). The literature on disability (i.e., Disability Studies) is expansive and I will not be able to cover all facets, but I will be drawing from various aspects of this literature to help understand the findings, including expanding on different types of disabilities (i.e., physical, developmental, intellectual). Importantly, I am not equating albinism to other forms of disabilities, but this body of literature holds various valuable lessons in this field of study. It is also important to note that disability is more than its physical and health manifestations. Thus, we must have a broader perspective in how it impacts PWA, siblings, and their family.

Self-perceptions as a Person with Albinism

One of the main findings in this study was the internalization and self-perceptions of PWA in which they journeyed toward understanding and accepting themselves as a PWA. Their internalization of their condition was mainly due to the challenges they faced concerning their sensitive skin and limited vision as well as the responses of their community. I highlight that the experience of being a PWA could not be segregated from the community responses. Society's views and responses were part of PWA and their families' daily encounters when they ventured outside their homes, especially when they were younger. In Rielly's (2020) study on the mental health of children with albinism in South Africa, she states that the unique and adverse situations of children with albinism caused by the interactions with the community and family (discrimination and alienation) significantly impacted their development and affected their emotional and mental health. Ezeilo (1989) also studied the psychological aspects of PWA in

Nigeria. He explains that although PWA experienced distress regarding their skin and eyes, a greater importance to their personality characteristics is the society's negative attitude.

Kromberg (2018b), in her sentinel research on albinism, suggests that there are three main aspects of the self. The first is the private self which includes each person's personality traits, cognition, and their self-assessments. The second self is the public self: individuals view or assess themselves in relation to the view of others. The third self is the collective self which is the view or assessment of a specific group, such as the family. The experience is different across cultures, but Kromberg (2018b) argued that the collective self partially determines social identity which is a part of one's self-concept that stems from being a member of a social group. Although PWA may experience acceptance and membership in their family group (intra), conflict may occur with their community group (extra) when they seek to be a part of that group. Being a member of a group partially defines one's social identity, but it is impacted by how they define themselves and by others in that community group. In relation to disability studies, research show that when people view a negative event (i.e., stigma) as stressful, the event can be seen as a threat to one's self-image (Kong et al., 2021). The threat then can highly impact one's self-evaluation and self-actualization, which may be linked to one's mental health. Through a symbolic interactionism perspective, people from disadvantaged groups such as those with a disability could be at a higher risk of internalizing the negative opinion of others, which could influence their self-perceptions (Kong et al., 2021). The views of PWA about themselves in my study were interconnected with how people reacted and perceived albinism. Thus, PWA needed to gradually construct their self-concept and develop self-awareness through their interaction and feedback from others.

Situating the Implications of Albinism on the Family

Having a sibling with a disability is known to have an impact on the family system and structure, especially when it is a lifelong disability (Avieli et al., 2019). Siblings may experience changes in family roles, family activities, and loss or absence of parental attention (Macks & Reeve, 2007). Albinism, as a form of disability, is in part related to PWA's vision problems and sensitivity to the sun that increases their risk for skin cancer (Mswela, 2017). PWA need to wear eyeglasses and even prescription sunglasses to assist with their vision and wear sunscreen and long-sleeved clothing daily, particularly when going outside (Kirkwood, 2009). PWA, their siblings, and family in my study incorporated these practices into their everyday routine. Parents and siblings, especially the siblings who were older than the brother or sister with albinism provided care or extra help for PWA. PWA and siblings without the condition described that their parents educated them to protect PWA's skin from the sun and there were instances where siblings were told to use certain creams during bath times for PWA when they were children or to avoid salt in PWA's food. Siblings were also shown in my study to provide protection for PWA, especially due to the stigma and discrimination from the society and the safety and security concerns for their sibling with albinism. Siblings directly addressed those who made negative remarks against their sibling with albinism. In Chapter Two, my literature review showed that siblings participated in caring practices for PWA, including integrating ways to avoid the sun (Lund, 2001). Broadening to disability studies, many authors have described that siblings are often involved in caring and supporting a family member with a disability in various daily activities that required assistance (Rossetti et al., 2018). Caring for a child with a disability is often a family effort where siblings are involved (Dervishaliaj & Murati, 2014). Aksoy &

Bercin Yildirim (2008) also describe that it is not uncommon for siblings to be protective over their sibling with a disability.

Many studies surrounding siblings of persons with a disability describe in varying extents that siblings become caregivers or caretakers (Avieli et al., 2019; De Caroli & Sagone, 2013). Participants, especially siblings of PWA, in my study did not describe activities they did for or with their siblings as a burden, nor did they consider that they were given greater responsibilities than other families without albinism or that they were taking on a caregiver role. PWA and their siblings “just” made sure that PWA were protected from the sun. Contrasting to other forms of disabilities, the adaptation and modification to the day-to-day of PWA and the family is not significantly laborious. Some studies have shown that the severity of their brother or sister’s disability is associated to poorer physical and psychological health, including adjustment of the siblings (Dew, et al., 2008; Macks & Reeve, 2007). A sibling who requires more assistance with their activities of daily living such as bathing and eating revealed a greater impact on the sibling without the disability (Macks & Reeve, 2007). For a family with a sibling with intellectual or developmental disabilities such as Down Syndrome, Autism and Cerebral Palsy, family members take on caregiving roles and adjust their homes to their needs, such as installing mechanical lifts and ensuring that there is someone available for the family member with the disability at all times (Dew, et al., 2008 Rossetti et al., 2018). Albinism is also not a terminal condition such as heart disease or cancer (if they integrated strategies to prevent skin cancer) where it can cause fear or uncertainty about the future (Schamong et al., 2022; Woodgate, 2006). I am not concluding that having a family member with albinism does not impact the family, but rather that with albinism, minimal disruption is made in the physical structure of the home and the role and responsibilities due to the health implications of the condition. But as soon as there were threats to safety and security, the impact of albinism in the family was substantial. This aspect will be discussed later in this chapter.

The adjustments, coping, and acceptance of the siblings and family without albinism was associated with the knowledge about albinism. Much of the literature on albinism have been about the broader context of the African society (extra-family) rather than within the family (intra-family) (Bradbury-Jones et al., 2018; OHCHR, n.d.b, Reimer-Kirkham et al., 2019). Aborisade's (2021) study in Nigeria is one of the very few exceptions. Participants with albinism in his study were taunted by family members because of their involuntary rapid eye movements and sensitivity to the sun and called names such as "spirit being" and "oosha god" (Aborisade, 2021, p. 1087). They were also excluded by their family from social gatherings and prevented from attending school because of social perceptions about albinism. PWA in the same study received disgust, irritation, and disapproval with some resulting in physical violence due to superstitious beliefs and spiritually induced beating because they were believed to be possessed by an evil spirit. Aborisade's study indicated that the family believed the misconceptions regarding albinism. These findings were not the case for the dyads in my thesis because siblings without albinism and their parents knew of the mythical understandings of albinism but, for the most part, had a basic scientific understanding of albinism such that those myths were outweighed by the accurate information. The families did not believe what they heard from their community such as that PWA were a curse or that they brought bad luck to the community. The family accepted PWA and described them as a "blessing." The diagnosis of the disability, including how easily understandable the disability is, plays an important role in the relationship of siblings (Aksoy & Bercin Yildirim, 2008). Thus, educating the family, including the siblings about albinism would help them understand the cause of the condition and influence how they would treat their family member with albinism (Aborisande, 2021).

Finally, siblings of PWA in this study did not describe that their sibling were any different from them. Often, they described their sibling with albinism as normal, meaning they were just as any other individual. Stalker and Connors (2004) explained that siblings of persons with a disability may be aware of the impairments of their brother or sister but that does not make them “different.” Instead, they saw their siblings as unique individuals, just like everyone else. They explained, “often this difference was seen, so to speak, as making no difference, either to the sibling’s worth as a human being, his life experiences or their relationship” (Stalker & Connors, 2004, p. 228). Their condition as a PWA is an integral part of the person, one of the many attributes that make a person who she or he is.

Promoting Equality and Equity

Some studies focusing on disability and sibling experiences reported unequal treatments between siblings as well as feelings of jealousy or resentment toward the sibling with a disability (Barr & McLeod, 2010; Dervishaliaj & Murati, 2014; Macks & Reeve, 2007; Mauldin & Saxena, 2018; Moyson & Roeyers, 2012). Participants in my study, however, explained that despite adapting to the needs of PWA, they described their experience as “normal” and that their parents promoted equality among siblings. By equality, participants expressed that PWA were not treated any differently by their family members due to the condition. No negative attitudes or behaviours were displayed between the dyads or amongst their other siblings. They shared household chores and attended the same gatherings. In a study focused on sibling of persons with an intellectual disability, Moyson and Roeyers (2012) found that participants were intentional to include activities that they would also do if their sibling did not have a disability. It was important for the siblings to prevent the disability from becoming a source of hindrance to family life such as play activities.

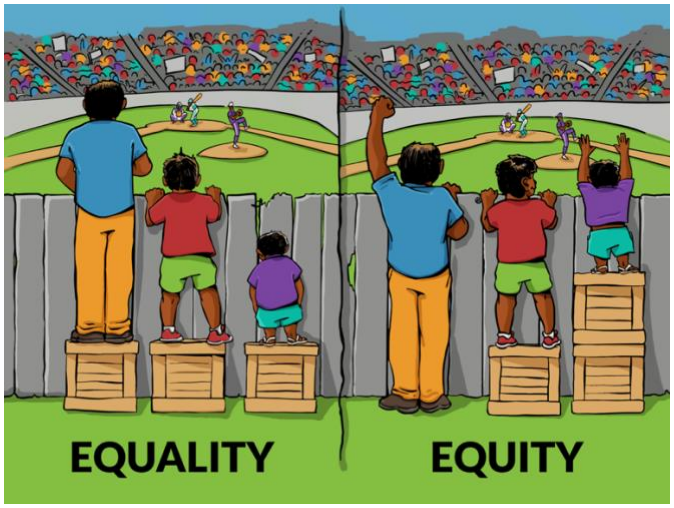

Figure 6: Equality versus equity (Interaction Institute for Social Change & Maguire, 2016)

As mentioned, participants in my study were conscious about the health implications of albinism and therefore would ensure that they implemented measures to protect PWA’s skin and support their vision. During play times, doing chores, or going out to the farm, PWA and their siblings adapted so that PWA could be included. This inclusion depicts that not only were the households of the dyads in this study enacting equality but that they also promoted equity. As seen in Figure 6, equity differs from equality. Where equality relates to having the same opportunities, equity promotes justice and fairness, recognizing that some people face more challenging circumstances than others and therefore require additional support to have the same opportunities (Espinoza, 2007). In this study, siblings made adjustments such as ensuring PWA wore sunscreen and protective clothing and using products for sensitive skin during baths so that their brother or sister with albinism was able to be present and included. These adaptations gave PWA fair opportunities to play, be involved in family activities, and overall grow, develop and flourish.

Empathy and Compassion

PWA in my study described that they were well accepted by their siblings and family. They were not discriminated against or excluded. Siblings of PWA in this study did not share any complaints for having a sibling with albinism and described their experiences with a sense of fondness. There were instances where parents gave instructions about how to protect PWA's skin but there were also times where activities done by their siblings were of their own accord, such as educating others about the condition or carrying sunscreen in their bag for their sibling with albinism. Dervishaliaj & Murati (2014) described that siblings of persons with a disability may feel a sense of inner responsibility. The care for their sibling was something that comes naturally, a responsibility that was part of them. Perenc and Pe˛czkowski (2008) focused on siblings of persons with physical disabilities and noted that siblings had a difference in empathetic concern. They indicate that siblings, especially those who were actively involved in the care of their sibling with a disability, tend to have a better understanding of other people and particularly those who have a disability. Siblings may develop empathy due to having an awareness when there were things they were not able to do (Mulroy et al., 2008). Their interaction with their sibling with a disability developed other prosocial skills, including increased sensitivity and respect for diversity (Perenc & Pe˛czkowski, 2008). Furthermore, the positive attitudes of parents impacted the responses of siblings with a disability (Dervishaliaj & Murati, 2014). Parents of the dyads in my study, for the most part, acted positively toward their children with albinism, showing no favouritism or unequal attention as per the dyads. They may then have influenced the siblings to act positively toward their brother or sister with albinism. The integration of normalcy in the family may perhaps be the reason PWA and their siblings did not share their psychosocial concerns with each other because they considered the experiences as part of their day-to-day and they did not want to worry their siblings and family. Furthermore, in Africa, mental health challenges are not widely talked about and addressed because it may be a taboo subject and could attract further social stigma (Amuyunzu-Nyamongo, 2013).

Moreover, siblings of persons with disabilities may have heightened awareness and feel compassion and tolerance toward people (Dew et al., 2008; Mulroy et al., 2008). They may be more appreciative of their own good health and circumstances and the experiences shared could result in closer family ties. When asked what recommendations would be helpful for other families impacted by albinism, siblings without the condition shared that support needed to be provided for PWA, especially access to skin and vision care and sensitizing the community about the condition. Siblings of PWA also shared that they were either present when PWA were stigmatized or they themselves had name-calling and exclusion directed toward them. Some siblings described feeling bad about what PWA were going through and had strong urges to retaliate. Siblings of persons with a disability are also impacted when the reaction of the outside world is negative, such as name-calling and bullying (Moyson & Roeyers, 2012). Dervishaliaj & Murati (2014) described that for siblings, the most stressful experience of having a sibling with a disability was the prejudice, discrimination, and stigma from other people. Thus, siblings have a desire to protect given the compassion they feel toward their sibling with a disability when they are badly treated by others. In the case of my study, siblings of PWA defended PWA and participated in educating their communities about the condition. They had feelings of loyalty to stand up for their sibling with albinism.

Family Dynamics and Family Theory

Although this thesis is centred on the experiences of siblings, I could not discount the entire family because the dyads' everyday experiences had significant interconnectedness with other family members, especially their experiences with their parents. All family members shared physical and social environments. The experiences of PWA and their siblings are influenced by where, when, and how they grew and developed to who they are today. In this section, I analyse how the dyads in this study described their familial experiences. Given the scope of a master's thesis, my analysis is necessarily limited. Understanding family structure and dynamics is complex given the differences in political, historical, and social context of the five countries represented in this study, in addition to the different community contexts in which they lived. Furthermore, there is seemingly limited theoretical development and empirical literature on family theories in Africa. Therefore, I am not generalizing the family structure and dynamics of the whole of Africa, but rather attempt to situate the experience of the dyads through focusing on just three aspects: applying the family development theory, examining the traditional African family context, and analyzing the parenting strategies through a hybrid of communalism and individualism.

Family Development Theory

Family theory, as implied, is concerned about families (White, 2005). It takes into account intergenerational and social relationships, recognizing both a biological and a social unit (White, 2005). Families have a connection with history as well as the future. It is a social group where love, devotion, and commitment are expressively shared. Family theory literature is expansive with various theories developed since the nineteenth century (such as family systems theory, feminist theory, and family development theory, just to name a few) (Georgas, 2004). Most family theories have a western origin, however, they have adopted and integrated the implications of contexts given that the "normal" sequence of events that a family goes through in a life course varies based on influencers such as geographic location or culture. Family structure is not limited to the west; they may be different in regions across the world and even diverse across time as contexts continue to evolve. For this analysis, I draw on the family development theory to interpret the experiences of siblings and families throughout their life course development up until the stage they were at.

Family development theory has its origins in family studies and sociology of family. This theory acknowledges the significance of individual development but focuses on the development of the family as a group of interacting individuals organized by social norms. Its attention is on the "systematic and patterned changes over time by families as they move through stages and events of their families' journey or experiences" (White et al., 2015, p. 102). Family development theory, and family developmental framework in general, focuses on the ontogenetic development of individuals and family factors, assuming that the "developmental processes are inevitable and important in understanding families" (White et al., 2015, p. 107). Families go through stages where each stage has a beginning that is marked by a transitional event, an end indicated by concluding a transitional event, and the duration of the stages is defined by the period between two transitional events. I highlight that the length of the stages and processes of development vary depending on the circumstances experienced by each family. My study captured multiple family stages. The circumstances of parents and the older siblings of PWA, for example, shifted when a child with albinism entered their lives. They all had intersecting, shared, and concurrently personal experiences of how they assimilated and settled with having a PWA as a member of the family. Different stages were represented in this study such as primary school, then going into university and when siblings moved to obtaining jobs, finding a partner, and having their own children. All the while, these stages were interlaced among family members, owing to their strong family bond, support for one another, and description of their family as communal in nature. It is how they integrated normalcy and acceptance starting when the PWA was young and into the various activities they did as a family that enabled the family to go through the stages with the sense of oneness and comradery, accounting for the uniqueness of the experience when a family member(s) has albinism in an African context. While they had their own perspectives and experiences both in intra- and extra-family, they developed alongside each other.

There is something to be said about the kinship shared among family members of the dyads, as it seemed to have an association to how PWA and siblings in my study grew up not only as wise and independent individuals, but also as resilient, strong leaders. Although stress is experienced individually, family is a unit that can display group symptoms of stress (Boss, 1988). In looking at family stress, the challenges are faced by the whole family as a group. In this thesis, challenges experienced by the dyads—to access education and economic opportunities, obtain sunscreen, and face social criticism because of the beliefs about albinism—were not just experienced by PWA. Understandably, parents would be impacted as they held the responsibility to raise and care for their children however the dyads' families, siblings, and extended family such as grandparents and aunts were also involved. They were able to overcome those challenges together. In family theories, families, as a group, were described to have resources, including cohesion (having a bond of unity throughout the family life course) and adaptability (such as the whole family's capacity to meet the demands of stressors), as well as traits of a healthy family such as having a sense of humour, family rituals, beliefs and traditions, and having shared and clear values (Patterson, 1988). These family resources, in addition to personal resources such as innate intelligence, personality traits, physical and emotional health, and knowledge and skills acquired by individuals through education, training, and experiences, may be what allowed for the successful management of stress (White et al., 2015). This explanation captures the strength of families of the participants in my study in which their resources allowed them to be resilient as they faced adversity growing and developing as families impacted by albinism.

Furthermore, an assumption of this framework is that the family group is “affected by all the levels of analysis, including the social norms of the larger society and the social norms of clusters such as social class” (White et al., 2015, p. 108). There were dyads in my study where their parents were in farming and retail and surrounded by mythical assumptions about albinism, which impacted their access to accurate information and the strategies needed to parent their children. The description of the dyads about their families were positive but there were instances where the influence of social norms caused them to treat their family member with albinism differently and heightened their awareness about the need for measures to keep them all safe.

Traditional African Family

The formations of families in Africa are diverse and unique compared to western family structures. Most literature describes African families to be communitarian in nature where there is a strong emphasis on broadening from a nuclear family to extended family and recognizing the community context (Amos, 2013). The family is also influenced by other social factors such as religion, culture, and social norms in addition to other determinants like age and gender. In this section, I attempt to describe key aspects of a traditional African family, focusing on identifying the family as a community and distinguishing some of the roles and responsibilities of siblings within the family. As noted earlier, my analysis is that of an outsider, reliant upon participants’ narratives, the limited literature describing African families, and my own observations these past years as Project Coordinator for a research project in Africa.

Family as a Community

It is common that when one speaks about family in the context of Africa, one is not referring to a nuclear family, but rather the extended family (Amos, 2013). It is created through expansion and includes many generations in addition to aunts, uncles, cousins, and in-laws. The uniqueness of this system in a traditional African community is that the responsibility for raising a child does not only belong to the biological parents but that the responsibility is shared by all. Marriages are seen as a serious commitment where a covenant is formed between two families, kinship, and villages (Mafumbate, 2019). The family plays a paramount role in mediating and buffering the interaction between the children and the world. This was highly represented in the experiences of the dyads in my study as they described their family as communal. For instance, Dyad B grew up with their aunt and Dyad E grew up with their grandparents. The rest of the dyads described activities they participated in often involved spending time with extended family members. Even when the dyads would obtain sunscreen from the hospital, for Dyad B for example, the aunt came along, and they were all then educated about albinism.

In addition, families in Africa are settled within the context of the community. The value and idea of security depend on one's identification with and within the community, emphasizing a sense of belonging to a larger group (Mafumbate, 2019). They valued human relations and families are often involved in community activities (Etta, Esowe & Asukwo, 2016). This may explain why PWA, siblings and even their parents deemed being a part of the community to be crucial in their lives. For example, PWA, siblings, and their family highlighted spending time together through being in their community, especially during celebrations and events. If the community, however, did not understand or accept them, the dyads were seen to deeply internalize how others responded to albinism. Thus, it was challenging to experience being excluded and ridiculed by community members because belonging in a community was part of who they are. It was even more impactful as the responses were not just by their playmates but also by the adults they encountered. Both PWA and their siblings appealed to the community continuously, showing that they were a normal family to instate that they were part of the community. It indicated that the community was involved in the families' everyday and had a strong implication to how the family lived, worked, and played.

Roles and Responsibilities

One of the common themes streamlined across the dyads was what their roles and responsibilities were within their homes, which was a big part of their day-to-day routine. This theme includes how they took care of each other and how they did the upkeep of their house by designating which family member did the household chores. In some families in Africa, the domestic work such as cooking, washing the dishes, and tidying of the house are exclusively assigned to women, while tasks like farm work are expected to be allocated for men (Wekwete, 2017). Gender disparity is common in Africa as women carry a heavy burden due to their reproductive roles and are expected to do household chores. This disparity was somewhat evident in my findings in that the female siblings were raised and expected to perform household duties. But the most common input from the participants were that they all shared the household tasks, regardless of their genders. Siblings may be assigned to certain chores and then switched responsibilities the next time. It is difficult to ascertain if gender expectations were influenced by having albinism as the women with albinism in my study described that the household responsibilities were divided equally among their siblings. They did have modifications, such as avoiding chores like cooking outside so that PWA did not get sunburned.

In addition to gendered roles, age had an impact on the siblings' roles and responsibilities. In many African families, older siblings may be expected to look after their younger siblings, especially when there is no adult supervision so parents could be economically productive (Evans, 2012). Tasks of older siblings may include instructing, playing, and supervising their younger siblings. Those who are older are often the first to work on household tasks or participate in the family's economic activities like farming. These descriptions aligned with the stories shared by the dyads in my study. Older siblings, those without albinism, explained that they were taught how to care for their younger sibling with albinism, including preventing them from playing under direct sunlight and to put on sunscreen. They were instructed to use special bath products when bathing their sibling with albinism. This responsibility, however, was not only applied to those without albinism. For example, Edward (PWA), as the second oldest, supported his siblings without albinism. This included assisting with homework, paying for tuition fees, and covering the costs of living expenses of their shared home. In relation to the discussion of age, older siblings, or those who are older in the family and elderly in general, are respected. They have authority, especially the elders who have the wisdom of the customs and traditions (Mafumbate, 2019). In my study, the dyads spoke more so about their nuclear family, discussing the interactions with their parents and siblings. As described in the findings, there was a strong theme of respect and recognition of the family members who were older. Even during times when disagreements or quarrels occurred, the respect for the older sibling was maintained.

Families in Africa are known to be a source of strength for guidance and support where, in times of challenges such as unemployment, poverty, and grief, most people depend on their family as a main source of material, social and emotional support, and social security (Africa

Union, 2003). Communitarian views call on an individual to care for the well-being of others as well as oneself (Kiambi, 2008). The family typically provides the basic necessities for life and health, love and belonging, and access to shelter, food, and water (Amos, 2013). Across all dyads, they recounted numerous ways they supported and were supported by their families. In addition to their parents, siblings encouraged one another emotionally, providing strength and wisdom. Socially, siblings of PWA were creating a buffer between the interactions of their sibling with albinism and society by being aware of the concerns relating to albinism and combating the beliefs about the condition through raising awareness. Spiritually, as the families included in my study were all Christians, some went to church together and described that they prayed for one another to keep them safe and in good health. Economically, which was the most common thread, the siblings as adults recounted the many occasions they financially supported each other, such as covering for tuition fees and books, obtaining sunscreen and health checkups, and assisting with living expenses and transportation. Siblings, whether they have or do not have albinism, looked back on their siblings to assist with whatever means they could, even if they lived in different cities and had built a life and family of their own.

The Hybrid of Collectivism and Individualism

As described earlier, families in Africa are often described to be communal and include the extended family and the community that they live in. There has been a rise, however, to the notion that the family structure and dynamics are influenced by colonization and pursuits for modernity where, particularly in this study, there seemed to be a coexistence of cultural value systems and at the same time, parents integrating developmental goals in the rearing of their children (Kiambi, 2008; Tamis-LeMonda et al., 2007). My findings showed a hybrid of collectivism and individualism among the dyads in how they were raised. It is important to note that the analysis of parenting strategies and family structure were only through the narratives and perspectives of the dyads.

Two of the dyads were raised by extended family members and the remaining five dyads described their experiences through their various ways of interactions with each other and often with extended family members and the community, such as during family gatherings and traditional community-related events. Despite them being adults, with the majority of the dyads living in different homes, they continued to connect in different ways such as frequent messaging on the phone and checking in on each other. A common insight among the dyads was that they were strongly encouraged to have a strong family relationship by their parents, and most especially among siblings. Siblings helped each other through school and integrated the needs of PWA through working together as a family. The dyads attributed their success to the relationship they have and the countless ways that they were supported by their family. It seemed that the parents enabled a culture that was collectivistic in which they promoted relatedness and interdependence (Grotevant, 1998; Tamis-LeMonda et al., 2007). The values that promote relatedness include connecting and being active within the family, having respect and obedience, and orientating oneself to the larger group where one aims to socialize, get along, and help other members. This view of collectivism highlights the notion that the self is part of a collective group.

At the same time, the dyads indicated that their parents urged them to be independent and autonomous. Most of them went to schools that were miles away from their homes, either at boarding schools for Dyad A or dorm at a university for Dyads D and F. Many had built a life and were obtaining their goals. The dyads were taught to have inner strength and determination and to be self-sustaining so that they can stand on their own two feet when in the community and to take on work and societal responsibilities. This independence aligns with an individualistic view where parenting goals emphasize the opportunity to make personal choices, have intrinsic forms of motivation and persistence, develop self-esteem, and enhance self-maximization (Tamis-LeMonda et al., 2007). In my study, parents had encouraged their children to be driven to achieve their aspirations and acknowledge their full potential.

Although individualism and collectivism may seem to be contrasting one another, studies have shown the coexistence of individualism and collectivism (Tamis-LeMonda et al., 2007). Tamis-LeMonda and colleagues argue that “both collectivism and individualism at the cultural level and autonomy and relatedness at the individual level might be viewed as fundamental, yet independent, aspects of successful child development” (p. 191). Some have argued that being autonomous does not necessarily mean being detached or separated (Tamis-LeMonda et al., 2007). Individuals must be able to socialize while simultaneously differentiate themselves from the community to which they are a member. While individuals are encouraged to be engaged, respectful, and generous with their family and society, they are urged to become capable in developing skills necessary to reach a goal and be successful.

Family-Centred Care

A related and reoccurring theme of this study was how the dyads situated their lives within the context of their family as they depicted just how intertwined their lives were, especially during their childhood given that they lived in one household, sharing the same physical and social environments. When one sibling was needing help, the other stepped up to lend a hand, no matter what it was. While they each seemed to keep some things to themselves, including how they dealt with albinism and how they felt about the condition, this study also showed that each member of the family had interconnectedness on how they were able to understand albinism, and then adopt and develop coping strategies. Although the individual who is directly impacted by albinism is the one who is diagnosed with it, all family members lived with the condition together because of the modifications they made to ensure that the PWA's needs were met. Parents and siblings played an integral role in providing care for PWA and thus it is also just (fair) that their health and well-being are accounted for. Family-centred care proposes that healthcare providers not only address the needs of one person, but also their family members (Meltzer, 2021; Uniacke et al., 2018). There are numerous definitions for family-centred care but the commonality in their description includes the acknowledgement and involvement of the family within the provision of care (Kokorelias et al., 2019). Thus, when sunscreen and genetic counselling is provided for the parents and PWA, for example, it is helpful to also consider the siblings and other members of the family (Kromberg, 2018b).

Families may experience a negative impact on their own well-being because of the ongoing demands associated with caring for their family members. When asked, they can typically articulate their needs (Kokorelias et al., 2019). Indeed, each participant in my study was asked about their recommendations on how best to support them and their family. They reported that their family needed to be economically supported and to have access to health and social services. Specifically, PWA needed access to sunscreens and regular skin checkups. It was found in this thesis that siblings without the condition expressed the need for social services for themselves, such as mental health counselling. This, therefore indicated that siblings should also have specific interventions that addressed their concerns and needs (Meltzer, 2021). It is important to integrate sibling support, recognizing that they too were seen to be impacted by albinism. But interestingly, the focus of the siblings without the condition was to support their sibling with albinism, advocating that attention must centre on those with the condition. Ibhawoh and colleagues (2022) argued that the unique challenges that PWA face are in part due to their proportionality in comparison to other people groups. Albinism is a relatively rare condition where reports of attacks, discrimination, and other concerns could be seen as minimal and therefore the “element of relative proportionality underscores the severity of the human rights issues at stake” (Ibhawoh et al., 2022, p.12). With limited structures supporting and protecting PWA, the burden then falls onto the family. It was seen in other studies that mothers took on the role to address the needs of their children with albinism (Ero et al., in press; Reimer-Kirkham et al., 2020). In this thesis, I argue that so do their siblings as they facilitated access to sunscreen and health checkups, covered the costs of tuition fees, paid for living expenses and transportation, and dispelled the beliefs about albinism through awareness raising within the community. All these initiatives point toward the need to support the whole family to protect and promote the rights of PWA and the family.

Social Determinants of Health and the Families of PWA

Many of the experiences of PWA and their siblings are centred around the societal context in Africa where the family plays an integral role in addressing the challenges faced by PWA. The lens of SDoH highlights social inequities and shows that multiple influences may be at the root of the health problems and therefore, must be recognized and be part of the process to improve outcomes (Deatrick, 2017). In this section, I describe how families in my study impact and are impacted by SDoH.

Families as a Social Determinant of Health

In most articles focusing on SDoH, families have not been included as a direct SDoH but rather embedded in one’s social system (Russell et al., 2018; WHO, 2007). There is some movement to change this (See Deatrick, 2017; McNeill, 2010). Families are directly and indirectly associated with health, educational, and social health outcomes for children and other family members. A family is pivotal in the care of its members, especially for children, to have healthy, happy, and productive lives. Particularly, the ability of parents or guardians to provide "loving care, a secure attachment, sufficient structure for healthy growth and development, non-coercive discipline and an overall safe family environment characterized by empathic relationships" are among the important factors in a home for children to be healthy and well adjusted (McNeill, 2010, p. 61). Moreover, the capacities of parents to provide for their children's basic needs such as housing, nutritious food, quality healthcare and education are essential for children to develop (McNeill, 2010). Siblings also play a role as their interaction with one another is part of their interconnected lived experiences. When families are unable to fulfill their role, children are at risk of poorer health outcomes. In my study, participants, especially PWA, described an overall positive experience at home. Parents treated everyone equally and encouraged the children to work hard and strive for their ambitions, such as pursuing their post-secondary education. The parents provided the means to ensure PWA were protected including educating all their children and providing sunscreen and long-sleeved clothing. No discrimination was reported to have been experienced from their siblings and they even partook in caring for their brother or sister with albinism including purchasing sunscreen and paying for their tuition fees. Despite the safety concerns, the family members enabled a safe environment at home to live and play, while at the same time, provided protection when they were in the community. The positive experiences growing up seemed to have contributed to PWA in this study. They embodied inner strength and determination to be resilient which led to their overall success, bringing them to go further in being advocates for other PWA.

The experiences of participants in this thesis are best case scenarios when looking at families as SDoH. However, their narratives do not represent all the experiences of PWA, especially in the African context. Although there are studies that suggest PWA have great relationships with family members (Mather et al., 2020; Pooe-Monyemore, Mavundla & Christianson, 2012), providing them with ample support, many authors suggest that a significant number of PWA were rejected and abandoned, especially at birth by their fathers, and excluded from the family (Aborisade, 2021; Bradbury-Jones et al., 2018; Kromberg et al., 2020; Ojilere & Saleh, 2019; Reimer-Kirkham et al., 2020, 2021). Parents may not have the literacy to understand the genetics of albinism, and some are reported to believe the myths such that their children will one day disappear when they die (Bradbury-Jones et al., 2018; Ojilere & Saleh, 2019). Some PWA experience name-calling and ridicule from siblings (Aborisade, 2021). Many children with albinism are raised by single mothers, lived in more rural areas, and faced poverty which hold dire consequences for future opportunities (Reimer-Kirkham et al., 2020; Tambala-Kaliati et al., 2021). Families are part of the “ecological worlds” of individuals that can impact the health of its members (Deatrick, 2017, p. 427). Therefore, great consideration must be made on families being a key determinant as they contribute to the outcomes of PWA.

Families Impacted by Social Determinants of Health

Although families were seen as part of the SDoH of PWA, families were also shown to be impacted by SDoH. Most families in my study grew up in a humble home with some expressing the financial stress of obtaining the basic needs. Siblings knew that they needed to budget, including modifying the choices of nutritious food, so that the family could buy sunscreen for PWA. Parents had to go away to earn a living in a different area and designate another family member(s) to care for their children. As families may not have financial stability, siblings often took on the responsibility to economically support their other siblings, including assisting in covering the cost of their place of living. Climate change also greatly impacted the family due to the unbearable heat of the sun, causing PWA and siblings increased concerns of PWA's skin with their risk for skin cancer (Astle et al., 2023). Moreover, families experienced name-calling and exclusion due to having a family member with albinism. Siblings without the condition were impacted by association to a PWA, including their ability to make friends or find a partner. Parents may also be stigmatized due to having a child with albinism, such as the heartbreaking story that Edward (PWA) shared. His mother did not acknowledge him and his sibling as her children due to fear of what their neighbours would think. A threat of the whole family's safety and security was also seen as a theme in this thesis for having a family member with albinism, fearing possible attacks against them all. Deatrick (2017) argued that families can be victims to the changes of societal structures and political systems, especially potentially vulnerable families. These threats of SDoH to other members of families impacted by albinism, although limited, are seen in some studies. Mothers, for example, were often accused of infidelity for giving birth to a child with albinism and, in some cases, experienced partner-based violence (Reimer-Kirkham et al., 2020). Mothers received judgements and stigma from healthcare providers which led to consequences to quality of care and access to much needed services and education, which in turn impacted how they were able to confidently care for their child with albinism (Buyco et al., in press). Moreover, in my literature review, some authors explained that the safety of the family members, including siblings, were threatened and some had to relocate (International Federation of Red Cross and Red Crescent Societies, 2009). PWA were separated from their families, some taken without consent from their parents and placed in special or boarding schools for protection (Nkrumah, 2021; Seepersaud, 2017). These difficult circumstances did not only disrupt the lives of the family but were also traumatizing. When the challenges associated to the SDoH of PWA are not addressed, the whole family's health and well-being are impacted because they are burdened by their SDoH. This points toward the need to integrate a family-centred approach in supporting families to moderate the impact of SDoH.

Persons with Albinism and Siblings as Human Rights Defenders

As described in Chapter One, human rights defenders are people, individually or with others, who act to promote and protect human rights in a peaceful manner (OHCHR, n.d.a). They operate in their own contexts (Bennett et al., 2015). In this section, I describe how PWA and their siblings are human rights defenders and should be identified as such.

Persons with Albinism as Human Rights Defenders

My participants grew up during the reported peak of attacks and violence against PWA (UNGA, 2019; 2022b) and the rise of the albinism human rights movement where various stakeholders (including CSOs/NGOs, human rights advocates, policymakers, researchers) worldwide has been raising awareness and addressing the challenges faced by PWA (UNGA, 2020c). Both participants with and without albinism in this study were aware of the human rights concerns associated with the condition. They not only witnessed the various activities that aimed to protect PWA, especially on social media, but they also took it upon themselves to participate in the actions toward eliminating violations against all PWA. Even when they were children, they demonstrated to the children and adults of their community their humanness and debunked the myths about the condition. They encouraged people to touch them to prove they were not ghosts. PWA also participated in community activities and gatherings to show that they have the same capacities as others. When they reached the age of majority, they dedicated their life's work to the albinism cause through being involved in albinism organizations. PWA in this study became remarkable leaders to bring about social change for society to embrace PWA. It is only natural and obvious that PWA were acknowledged as human rights defenders.

The activities of human rights defenders can be varying, including disseminating information, documenting, or reporting violations, or “combating a culture of that may sustain human rights violations” (Donders, 2016, p. 283). In a recent report of the UN Independent Expert on the enjoyment of human rights by persons with albinism (UNGA, 2022b), PWA were specifically named as human rights defenders. Human rights defenders with albinism were recognized to have carried out crucial human rights work at the local, national, and international levels such as raising awareness about albinism and the needs of PWA to achieve the highest attainable standard of health. Similar to PWA in my study, many albinism organizations such as the Albinism Society of South Africa, Albinism Advocacy for Access, Albinism Foundation of Zambia, and Africa Albinism Network are managed by PWA or have been closely working alongside PWA (Africa Albinism Network, n.d.b). I highlight the work of the first UN Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, a PWA herself. She has been instrumental in raising global attention to the human rights challenges faced by PWA (UNGA, 2020c) and was at the forefront in addressing harmful witchcraft related practices internationally (Reimer-Kirkham et al., 2022). Despite the challenges PWA faced, including carrying out activities by personally covering the financial costs, enduring mental and emotional strain, and facing threats to their safety, PWA continue to be engaged in this important work (UNGA, 2022b).

Siblings as Human Rights Defenders

In addition to PWA, the UN Independent Expert acknowledged that families, too, have been acting as human rights defenders (UNGA, 2022b). In this thesis, siblings were described to be instrumental in championing their siblings with albinism. They protected and defended their siblings from their local society (being the steel rebar), seemingly without concern for their own safety or how they would be treated by others. Siblings, even when they already had families and children of their own, continued to support PWA by providing access to healthcare and education. Much more, they recognized the harms of the pre-existing beliefs about albinism and how it impacted those with the condition. They acknowledged the injustice that their siblings and other PWA were experiencing. Instead of being silent, hiding or disserting their sibling with albinism, they stepped up to provide education to the community. From the findings, siblings were not only concerned and acted to protect their siblings, but their actions were to support all PWA, especially those living in Africa.

In the broader literature, the discussion of human rights defenders and families is around how families are placed at increased risks and dangers for having a family member working as a human rights defender, and not necessarily identifying the family themselves as human rights defenders (Knox, 2017; Nah et al., 2013). Most authors identify the works of individuals or organizations as agents but do not include families as being part of the human rights work (Donders, 2016; Forst, 2018; Nah et al., 2013). It is only recently that family has been coined to be human rights defenders. This reference happens to be in relation to albinism, particularly mothers. Because mothers impacted by albinism were often failed by the state and continued to face limited resources, they became activists in devising solutions to problems they themselves were facing (Ero et al., in press). In Tanzania, mamas’ groups (peer support groups run by mothers with albinism or mothers with children with albinism) served not only as support groups but also as a source of human rights interventions that promoted their rights and their children’s

(Ero et al., in press; Reimer-Kirkham et al., 2021). This study adds to this literature to show that siblings too have been acting as human rights defenders for PWA.

Much of the human rights defenders' work is deeply personal as it is shaped by structural forces but dynamically interacting with local and personal experiences (Nah et al., 2013). Although their work is crucial to bridge and facilitate dialogue between the global norms and local context, the work of human rights defenders puts them and the people they are associated with at risk. For instance, the UN Independent Expert reported human rights defenders of PWA receiving death threats and needing to flee from their homes. People acting as human rights defenders, such as PWA, siblings, and families, must be identified as such to recognize their human rights work and to emphasize their protection as human rights defenders through international and national instruments (UNGA, 2022b).

Chapter Five Summary

In this chapter, I began with a synopsis of the findings of my study and presented my framework, identifying the interconnectedness among the dyads and their families. PWA, their siblings, and their families' experiences were shaped by their upbringing and interactions intra- and extra-family. I then expanded my analysis in multiple aspects of the experiences of PWA and their siblings in Africa through the lens of disability, family theory, SDoH, and human rights. Drawing from the disability studies literature, I explained that PWA were significantly psychologically and psychosocially impacted by the responses of the community because the ways that society viewed them were tied to their social identity and influenced how they viewed their own physical appearance. The acts of siblings of PWA were also described, shedding light on the care, compassion, and the many ways they provided support to the other with a disability, which in this context are their siblings with albinism, through normalcy and acceptance.

I also situated the experiences of the dyads within the Family Development Theory to describe that the dyads’ families went through various life stages together. Families had personal (i.e., personality, knowledge) and family resources (i.e., unity) that allowed them to surpass each stage with oneness and resilience. An important aspect for interpretation included what would commonly be important in an African family. The family is not just nuclear but rather includes the extended family and community, indicating that they are an integral part of the dyads’ identity and therefore experiences.

I then unpacked the significance of acknowledging how family impacts and are impacted by their SDoH. On the one hand, in addition to their parents, siblings provided support (the steel rebar) in accessing healthcare, education, and social acceptance, but on the other hand, they too experienced challenges in obtaining such services and endured discrimination, exclusion, and safety concerns by association to their sibling with albinism.

Finally, I asserted that PWA and siblings acted as human rights defenders. Instead of feeling discouraged by their negative social experiences, PWA became driven, independent, and resilient leaders who became actively involved in promoting and protecting the rights of all PWA. Siblings were also seen to be acting as human rights defenders for having the incentive to raise awareness on albinism in their communities.

My study added to the existing literature on the experiences of PWA within the family and in the community. My study also provided siblings without the condition a space to share their unique experiences, siblings whose voices have yet to be heard. In the final chapter of this thesis, I provide the summary of my findings and state my recommendations and conclusions.

CHAPTER SIX: SUMMARY, CONCLUSIONS, AND RECOMMENDATIONS

The purpose of this thesis was to explore the experiences of siblings impacted by albinism in the context of Africa. In this final chapter, I provide a summary of the findings and highlight key conclusions drawn from this study. I also propose recommendations and implications in the areas of non-governmental and civil society organizations, policy and government, health and social services, nurses, and research for siblings with albinism and siblings of PWA.

Summary of Findings

I conducted a qualitative study through Interpretive Description (Thorne, 2016). I interviewed seven dyads (fourteen participants) from five countries in Africa (Ghana, Nigeria, South Africa, Tanzania, and Zambia) through virtual individual and dyad interviews in a ten-week period of October-December 2022. This study examined the dynamics experienced by intra- and extra-family when a sibling(s) has albinism, considering the social, political, economic, and historical context, and its implications for healthcare providers. Through dyadic thematic analysis, four themes emerged. In Theme One, *Internalizing Processes: Persons with Albinism and Siblings*, participants shared their psychosocial and psychological challenges as they assimilated and understood albinism amid the negative social perceptions of albinism growing up. In Theme Two, *Normalizing Responses: Family Interactions, Support and Responsibilities*, the dyads described that they normalized the integration of albinism in their homes while also considering the health implications of the condition. For the most part, they all described positive experiences with their siblings and parents, involving PWA in all family activities. PWA and their siblings described how they supported each other, including ensuring that PWA were protected from the sun as well as financially supporting them and enabling them to pursue their aspirations. In Theme Three, *Stigmatizing Experiences: Community Context*, PWA and their siblings described the circulating and still prevalent misconceptions and misunderstandings about albinism. They described the stigma, discrimination, and exclusion experienced when they were in the community. PWA and their siblings shared safety and security concerns faced by the entire family due to having a sibling with albinism. They, however, identified the start of social change in relation to the increased sensitization of albinism among their community members as PWA and their siblings partook in educating people and protecting their siblings and other PWA. Finally, Theme Four, *Encompassing Support: Needs of Families Impacted by Albinism*, highlighted the recommendations expressed by the dyads, including the need to involve and educate the family about albinism, the enhancement of financial, health, and social support for PWA and their siblings, and the necessity to increase awareness about albinism in the society.

In many ways, there are great lessons learned from the dyads' families because PWA and their siblings described positive perceptions while living with albinism, a disability associated with visual impairment and sun sensitivity in addition to facing challenges resulting from societal interactions. PWA in this study reached self-actualization and moved forward in pursuing their goals. Family members supported one another, indicating that their families were pivotal in their overall experiences. PWA and their siblings are individuals who embodied the essence of human rights defenders. This study also highlighted the heightened challenges faced by PWA, siblings, and their families due to the condition. These challenges included the impact of the limited access to health and social services, negative societal attitudes and behaviours against PWA and their families, and threats to safety and security. When PWA were without access to quality education, health and social services, and non-discriminatory interactions, the burden was placed on the family, including siblings. The findings revealed what Deatrick (2017) argued, namely, that families both impact and are impacted by SDoH. The model of sibling support must be integrated to support siblings impacted by albinism (Meltzer, 2021), along with a family-centred approach where all family members are acknowledged, understood, and supported.

Conclusions

In this section, I bring forward conclusions derived from this study.

1. The impact of albinism extends far beyond its health implications. In the context of Africa, PWA faced emotional, psychological, and psychosocial challenges substantially influenced by societal perceptions about the condition.
2. Knowledge about albinism was critical for PWA, siblings, families, and the community. PWA needed the genetic information about albinism in order to accept and live with it. Families and communities were able to accept, support, and protect PWA if they were sensitized about albinism. Education on albinism led to social change and a shift in how PWA and the family were able to live, work, and play.
3. Siblings and families also experienced challenges by association to PWA, including stigma and discrimination from the community.
4. Families played a critical role in the growth and development of PWA, including acceptance of the condition and how they lived with albinism together. They were part of the living environment of PWA and, therefore, I argue that families are SDoH.
5. Families were also influenced by the challenges of PWA, and thereby were impacted by SDoH. They took on the burden when PWA were not obtaining the support they needed

from existing social structures, such as health and social services or government economic support.

6. Families in this study integrated a sense of normalcy which allowed PWA to not feel any different from their siblings whilst ensuring PWA's needs were met. When PWA were accepted and well supported at home, they then had the capacity to handle challenges outside their homes and to flourish and thrive.
7. PWA and their siblings have strong voices, and they had the strength to share their needs and concerns. PWA and their siblings in this study held great insight regarding how best to support them and their family. Thus, they became leaders and advocates; they were human rights defenders for others who shared the same experiences. This study highlighted the incredible capacities of PWA when given the resources and opportunities.

Recommendations and Implications

Based on the findings of this study, I present recommendations and implications in the areas of non-governmental and civil society organizations, policy and government, health and social services, nursing, and research to support siblings impacted by albinism. I have developed these recommendations and implications from a nursing professional standpoint and offer these to an interdisciplinary and intersectoral audience.

Non-governmental and Civil Society Organizations

In many areas in Africa, NGOs and CSOs have been the primary resource for PWA and their families, including access to free sunscreen, protective clothing, and skin checkups, especially in more remote and rural areas (Reimer-Kirkham et al., 2020; 2021). I encourage NGOs and CSOs to provide support to families impacted by albinism and emphasize not only the needs of PWA and parents but their siblings as well. There have been support groups available for PWA, mothers, fathers, and grandparents, however, according to my knowledge and research, none specifically for siblings (NOAH, n.d.b). Being a sibling to a PWA is a unique experience as described in this thesis and thus, they also require support. There are organizations that specifically provide support for siblings of persons with disabilities, such as the initiatives of Centre for Siblings of Persons with Disabilities (n.d.). There must also be support groups available for siblings of PWA. I encourage the increase in family-oriented workshops, activities, and events where families could be educated about albinism, and they could interact with other families.

The experience of PWA and their families are significantly influenced by the perceptions of their community about albinism. Such beliefs have not only subjected them to stigma and discrimination but also to threats to their ability to live and feel safe. NGOs and CSOs can partner with healthcare providers, including nurses, educators, police, and policymakers to disseminate information about albinism across the society.

Policy

There are international and national level directions in supporting PWA, siblings, and families. At the international level, I foreground the Universal Declaration of Human Rights (UN, 1948) for its emphasis on justice, peace in the world, and the entitlement to the protection of the family. Inherent to all human beings are the right to life, liberty, health, and humane treatment. The recognition of rights of every individual should be the foundation in creating and re-constructing policies to serve the common good. I also draw upon international instruments to ensure the protection for human rights defenders, particularly the Declaration on the Right and Responsibility of Individuals, Groups and Organs of Society to Promote and Protect Universally Recognized Human Rights and Fundamental Freedoms (commonly known as the Declaration on the Human Rights Defenders) (UNGA, 1999). This declaration highlights that human rights defenders play an essential role in the realization of the human rights under the Universal Declaration of Human Rights (UNGA, 2022b). Policies, legislations, and programs must be implemented to promote an enabling environment and ensure the protection of human rights defenders.

According to the UN (2022), the states must make a conscious effort in implementing family-oriented policies and programmes including the promotion to access affordable housing, intergenerational living arrangements, family unification policies, as well as sustainable climate change management that benefit families. Family policies must be incorporated in various levels of the government because it influences the standard of living of current and future generations (UNICEF, 2020). In addition, solutions to end poverty, access to health services and education, and elimination of violence are some key areas where family outcomes can be improved. Families should be involved in the multi-level discussions as each member of the family are the best individuals to identify their needs, communicate those needs, and provide insight to solutions that could work to improve their well-being and therefore, benefit development (Deatrick, 2017). Families, as a natural and foundational unit of a society, are recognized to be integral in achieving the sustainable developmental Goals (SDGs), as it relies on how well families are empowered to contribute to the outlined goals (UNICEF, 2020).

In Africa, the African Union (2004) promoted the Plan of Action on the Family in Africa in 2004. The main objective of this action plan was to advocate for the promotion, creation, implementation, and continuous monitoring of national structures, policies and programs to the challenges faced by African families. Some of their challenges include, but are not limited to, inadequate social security mechanisms, high poverty and unemployment rate, gender inequality, rural to urban migration, and displacement. These challenges are heightened for PWA and their families due to their vulnerability. I encourage policy makers to take great considerations to involve family-integrated policies and legislations.

Furthermore, the Plan of Action for albinism urges actions to addresses concerns not only for PWA but also their families. Families need to be provided with education about the condition (United Nations, 2016) and given the necessary support such as psychosocial, medical, legal, security, and socioeconomic support (African Union, 2019).

Government

In many areas in Africa, the government has failed to protect the rights of PWA and their families, given that PWA have experienced human rights violations for decades and still continue to experience them to this day. The government needs to take accountability for the needs of families impacted by albinism, as the responsibility is in the hands of the state. There have been actions from the government to address challenges specific to PWA in the last few years, including the Ekurhuleni Declaration on the Rights of Persons with Albinism, stemming from a conference held in 2013 in South Africa (South African Government, 2013; UNGA, 2020b). They brought persons from various sectors including PWA focusing on the elimination of discrimination against PWA. They addressed the right to education and health, and to correct the mythical beliefs associated with albinism. However, there are limited legislations specific to the protection of PWA and even more for the whole family in many countries in Africa (UNGA, 2017, 2023). NGOs and CSOs have been filling in the gaps which has been evident in the UN Independent Expert's reports as well as seen in this study, especially in the access to health and community awareness raising (UNGA, 2020b; Strobell, 2020). The government, in collaboration with healthcare providers and NGOs/CSOs needs to listen and engage with PWA, their siblings, and their families and enact measures that address their needs.

As previously mentioned, the Executive Council of the African Union adopted the Implementation Matrix of the Plan of Action to End Attacks and Other Human Rights Violations Targeting Persons with Albinism in Africa (Plan of Action 2021-2031) in 2019 (Africa Albinism Network, n.d.a; African Union, 2019). Since then, organizations have been coming together, being proactive to engage the government in foregrounding specific measures to eliminate attacks against PWA (Africa Albinism Network, 2023). The government across Africa need to adopt the Action Plan, facilitate learning, and fund programs to strengthen all stakeholders' capacities to promote the rights of PWA and their families.

Health and Social Services

Families play a critical role on the health and provision of care of an individual (Kokorelias et al., 2019). In healthcare, families impacted by albinism and disability in general, require a family-centred approach, involving each member of the family (parents, siblings, and extended family) to identify concerns, make decisions, and build capacities (Coyne et al., 2011). Family is often the primary support for individuals and, therefore, strengthening their resilience and providing empowerment among its members will be an important contribution to the development of Africa. Such contribution must begin by educating the parents about albinism and how to care for a child with albinism at the time of birth. This education will enable them to leave the hospital or clinic confident on their ability to provide care for their child. Giving them information would also allow parents to explain to their family, including their other children, about the condition. Referrals should be made to services such as dermatologists, ophthalmologists, and genetic counselling (Kromberg et al., 2020). It is part of the healthcare providers' (i.e., nurses, midwives, physicians) responsibility to provide health education and ensure that clients and their families have the resources they need prior to being discharged. PWA need to be provided with much needed sunscreen, protective clothing, and prescription eyeglasses as the entire family is challenged when PWA do not have access to such. Services such as The Regional Dermatology Training Centre in Tanzania focusing on regular prevention and treatment services to PWA, are essential to mitigate the risk of skin cancer, which is prevalent among PWA (UNGA, 2017).

Nurses, as well as other healthcare providers, must encourage the participation and collaboration among family members in understanding and living with albinism. Age-appropriate conversations and explanations about albinism are important for PWA and siblings as they grow up. PWA may benefit from genetic counselling to help them understand the nature and cause of albinism. Living in Africa where cultural and spiritual beliefs about albinism exist, genetic understandings about albinism help them counter those beliefs (Kromberg et al., 2020). Siblings without albinism would also benefit from genetic counselling as they too are affected by the condition being potential carriers of the gene and may have a child with albinism one day. They also need accurate information about albinism to be able to educate the community.

Growing up with albinism, especially in Africa, is challenging for PWA due to their physical differences among peers, stigma and discrimination experienced in the community, and health implications of albinism (visual impairment and vulnerability to skin cancer) (Hong et al., 2006). These challenges may impact their self-conceptualization and lead to mental health issues. Family members, including siblings and parents, may also face mental health concerns due to being subjected to name-calling, discrimination, and exclusion by association. Their constant vigilance for PWA safety and their own amplifies fear and distress. Therefore, mental health must be assessed among families impacted by albinism with referrals to mental health counselling, as necessary. As this thesis is centred around siblings, I emphasize that sibling support for health and social services must be its own entity and addressed in its own right when supporting the family and should not be tagged as part of supporting parents or persons with disability (Meltzer, 2021). Sibling support must be offered to all siblings of PWA regardless of whether PWA or their parents accept support.

PWA in this study also expressed challenges at school, such as the lack of understanding about albinism among teachers and students and access to assistive devices. Teachers must be given education about albinism so that they would be able to provide appropriate assistance to PWA, which would include providing assistive devices, larger printed materials, and protection of PWA's skin during outdoor activities. Students must also be sensitized about albinism given that participants in this study expressed discrimination and exclusion from their peers at school.

Nurses and Nursing

Being a nurse conducting this research study provided unique insights on many fronts. Firstly, being a nurse allowed for the recognition of the health implications associated with having albinism. In nursing, health education about wearing sunscreen, hats, protective clothing, and health education is an important intervention necessary for PWA to decrease the risk of skin cancer. Nurses are also involved to ensure that PWA and their family have the resources they need, such as access to sunscreen and sunglasses. Nurses are vital to assist in managing health conditions such as albinism or other disabilities. Secondly, nurses are key players in addressing the SDoH given that nurses are in the forefront in promoting health and well-being both directly and indirectly (Canadian Nurses Association [CNA], n.d.). Nurses have acknowledged that there is a strong association in achieving quality of life with social factors which includes stable housing, access to nutritious food, economic and job opportunities, quality education and health, and social support (Andermann, 2016; Tiase et al., 2022). As a nurse, I recognize that nurses are in a position to collaborate and communicate across different sectors such as in healthcare, government, and advocacy to foster communication and share resources to reduce health inequities, which is a big concern for PWA and their families in Africa.

Globally, nurses have a responsibility to be cognisant, raise awareness, and devise solutions to address the causes of global health issues (CNA, 2009) as nurses are known to be one of the largest groups of healthcare providers (WHO, n.d.c). Nurses hold the power as global leaders because of their positioning as primary care providers as well as trusted health professionals to influence change for better health outcomes for all. And although human rights perspectives have not traditionally been an explicit foundation for conceptualization and clinical practice, it is integral that nurses be involved in international issues and human rights discussion because of the implications of human rights to the society (Easley & Allen, 2007). As defined earlier, everyone is entitled to human rights, which are fundamental to the health and well-being of each individual. The Canadian Nurses Association (2017) has integrated human rights in the *Code of Ethics*, indicating nurses’ responsibility to be involved in ensuring optimal well-being for all humans and for health to be a fundamental right that should be equitably accessible.

Research

This study only gave a fragment of insight into the experiences of siblings impacted by albinism in Africa. It highlighted the experiences of PWA when they have a strong support system at home, when things are done right. Perspectives of PWA and siblings must also be explored when the family does not understand the cause of albinism or where PWA are not integrated or accepted into the family. Studies must take place in rural areas where attacks were reported, and scientific information is not widespread. This study was focused on dyads, giving perspectives from only two members of the family. As there are many instances where there are more than two siblings per household, further research must be conducted with all siblings and the rest of the family members. The upbringing and parenting strategies are important for the growth and development of PWA, and recognizing too that many fathers are reported to have rejected or abandoned their children with albinism (Braathen & Ingstad, 2006; Reimer-Kirkham et al., 2020). At the time of writing of this thesis, to my knowledge, there has not been research conducted focusing on fathers.

This study also indicated that further research must be conducted on the mental health of PWA across the lifespan. Community responses to albinism are associated with how PWA viewed themselves having albinism and how they lived with the condition. Mental health issues seemed to progress from early childhood when children with albinism first notice their physical difference from other people and all the way to adulthood where their interactions with the community are influenced by the colour of their skin and beliefs about albinism. Research on this topic is important to understand how healthcare providers can support the mental health of PWA and what coping strategies would be effective.

Final Summary

The [family] support system has always been there and it's an essential aspect. It is a key part of us being able to reach where we are today.

- David (PWA)

Until this study, the experiences of siblings impacted by albinism, in particular siblings of PWA in Africa, were nearly absent in the discussion on albinism. This study provided an opportunity to shed light to the unique experiences of a family impacted by this condition, including the importance of integrating normalcy and acceptance as well as the challenges they continued to face in the community. It brings to the forefront the value of family support for PWA to flourish and thrive. Significantly, this research highlighted the need to have a family-centred approach in addressing the challenges faced by PWA as well as the need for interventions to support siblings without the condition and their families.

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Appendix A

Literature Review Search Strategy

Inclusion/ Exclusion Criteria

Inclusion: Peer-reviewed; English and French language; Masters and PhD thesis or dissertation; substantive discussion of siblings' experience (minimum of 100 worlds); Grey literature Articles can be considered with a clinical, biological, or medical focus.

Exclusion: Not peer-reviewed; not in the specified language; limited discussion of siblings' experience; Bachelor's level thesis.

Search was completed for articles up to August 2022.

Key Word Search Strings

	AND		AND	
Attempt 1		Albinism OR albino*		Sibling* OR brother* OR sister*
Attempt 2		Albinism OR albino* OR disabilit*		Sibling* OR brother* OR sister* OR famil* OR kin*
Attempt 3 (Final)		Albinism OR albino*		Sibling* OR brother* OR sister* OR famil* OR kin*

Academic Literature

Database	Search strings	Total yielded
CINAHL Complete	(Albinism OR albino*) AND (Sibling* OR brother* OR sister* OR famil* OR kin*)	246
CINAHL subject headings	(MH "Albinism") AND ((MH "Family") OR (MH "Family Relations") OR (MH "Family Systems Theory") OR (MM "Family Attitudes") OR (MM "Family Integrity Promotion: Childbearing Family (Iowa NIC)") OR (MM "Family Nursing") OR (MM "Sibling Relations") OR (MM "Sibling Violence") OR (MM "Sibling Support (Iowa NIC)") OR (MM "Siblings"))	4
Academic Search Complete	(Albinism OR albino*) AND (Sibling* OR brother* OR sister* OR famil* OR kin*)	2108

Academic Search Complete (EBSCO host) Subject terms	(DE "ALBINOS & albinism") AND DE "SIBLINGS" OR (DE "SISTERS" OR DE "TWIN sisters" OR DE "BROTHERS" OR (DE "FAMILY services" OR DE "FAMILIES") OR (DE "FAMILY health") OR (DE "FAMILY attitudes")) AND (DE "FAMILY counseling" OR DE "FAMILY relations")	4
MEDLINE	(Albinism OR albino*) AND (Sibling* OR brother* OR sister* OR famil* OR kin*)	158
PsycInfo	(Albinism OR albino*) AND (Sibling* OR brother* OR sister* OR famil* OR kin*)	474
PsycInfo Thesaurus	(DE "Albinism") AND De “sibling Relations” OR DE Siblings OR DE “Family Members” OR DE Brothers OR DE Sisters	4
Sociological Abstracts	(Albinism OR albino*) AND (Sibling* OR brother* OR sister*)	292
	Total	3290
	Duplicates Removed	304
	Included	**20**

Google scholar

Keywords	**Total results**	**Results**
Sibling, Brother, sister, albinism	2380	3
Sibling, Brother, sister, albinism Africa	7,030	2
Sibling brother sister albino Africa	22,000	1
Sibling children Albinism	6,270	1
	Duplicates	6
	Included	**5**

Appendix B

Example of the Literature Review Matrix

No.	**Article**	**Country of author(s)**	**Geographical region of focus**	**Focus of Article**	**Type of Article**
1	Aborisade, R.A. (2021). "Why always me?": Childhood experiences of family violence and prejudicial treatment against people living with albinism in Nigeria. *Journal of Family Violence, 36*(8), 1081–1094. https://doi.org/10.1007/s10896-021-00264-7	Nigeria	Nigeria	"This study is geared towards addressing the gap in literature on albinism, disability and family violence that are yet to significantly focus on the childhood experiences of PWA in their family environment." (p. 1081)	Qualitative
2	Affram, A., Teye-Kwadjo, E. & Gyasi-Gyamerah, A. (2019). Influence of social stigma on subjective well-being of persons with albinism in Ghana. *Community and Applied Social Psychology, 29*(4), 323-335. https://doi.org/10.1002/casp.2403	Ghana	Ghana	"This study investigated the subjected well-being of PWA in Ghana. Participants (N = 105) completed a survey questionnaire on social stigma, social support, and SWB." (p. 323)	Quantitative
3	Amnesty International. (2016). *"We are not animals hunted or sold": Violence*	International	Malawi	This report focuses on the lived experiences of people with albinism in Malawi	Qualitative

	and discrimination against people with albinism in Malawi. https://www.amnesty.org/en/documents/afr36/4126/2016/en/			in the context of superstition-driven attacks against them and the corresponding government failure to protect the right to life for this vulnerable group and to guarantee their right to security of person.	
4	Baker, C., Lund, P., Massah, B. & Mawerenga, J. (2021). We are human, just like you: Albinism in Malawi – implications for security. *Journal of Humanities*, *29*(1), 57-84.	Malawi	UK, Malawi	"This article draws on the findings of participatory research undertaken between 2015 and 2019 to explore context-specific knowledge about the security of people with albinism in Malawi and to reveal perceptions of what makes people with albinism secure or insecure." (p. 57)	Qualitative
5	Beckham, A. (1946). Albinism in negro children. *Journal of Genetic Psychology*, *69*(2), 199-215. https://doi.org/10.1080/08856559.1946.10533389	US	US	"The purpose of this study was to observe the development of a group of albinos during a period of 10 years" (p. 199)	Qualitative

6	Başkurt, H., Celik, E., Yeşiladali, G., & Tercan, M. (2011). Importance of hereditary factors in synchronous development of Basal cell carcinoma in two albino brothers: Case report. *Annals of Plastic Surgery*, *66*(6), 640–642. https://doi.org/10.1097/SAP.0b013e3181e35cc1	Turkey	Turkey	"We have reported 2 brothers who have albinism and synchronous developed BCC on their trunk region." (p. 640)	Case Study
7	Blackenberg, N. (2000). That rare and random tribe: Albino identity in South Africa. *Critical Arts*, *12*(2), 6-48. https://doi.org/10.1080/02560040085310081	Canada/ South Africa	South Africa	"This essay will look at Albino identity from two perspectives. The first will examine the Albino within an African context. The second will use 'European' and American discourse on identity to explore the implications of the existence of the Black Albino on contemporary racial theory. Both explorations will ultimately explore what the existence of albinism does to our (modernist) conceptions of race and spirituality." (p. 6)	Qualitative

8	Cheong, P. Y., King, R. A., & Bateman, J. B. (1992). Oculocutaneous albinism: Variable expressivity of nystagmus in a sibship. *Journal of Pediatric Ophthalmology and Strabismus*, *29*(3), 185–188. https://doi.org/10.3928/0191-3913-19920501-14	US	US	"We report two siblings, a male and female, with minimal, if any, pigmentation of skin and hair, iris transillumination defects, blond fundi, and hypoplasia of the foveae and optic nerve heads who were discordant for nystagmus; the diagnosis of OCA was based on the clinical findings." (p. 185)	Case study
9	Clarke, D. J., & Buckley, M. E. (1989). Familial association of albinism and schizophrenia. *The British Journal of Psychiatry: The Journal of Mental Science*, *155*, 551–553. https://doi.org/10.1192/bjp.155.4.551	England	England	"We report a family of Irish origin in whom OCA is associated with a psychotic disorder phenomenologically indistinguishable from schizophrenia in two out of three siblings." (p. 551)	Case study
10	Cruz-Irigo, A., Ladizinkski, B. & Sethi, A. (2011). Albinism in Africa: Stigma, slaughter and awareness campaigns. *Dermatologic Clinics*, *29*(1), 79-87. https://doi.org/10.1016/j.det.2010.08.015	USA	Africa	explaining the myths and misconceptions about albinism, health concerns, and the awareness campaigns that has been initiated	discussion

11	Ellis, J. P., Gray, A., & Richards, F. (1995). Oculocutaneous albinism and bruising in two sisters--probable Hermansky-Pudlak syndrome. *Journal of the Royal Society of Medicine*, *88*(5), 293P–294P.	UK	UK	Case report on 2 siblings presenting with bruising and diagnosed with Hermansky-Pudlak syndrome.	Case study
12	Ezeilo B. N. (1989). Psychological aspects of albinism: An exploratory study with Nigerian (Igbo) albino subjects. *Social Science & Medicine*, *29*(9), 1129–1131. https://doi.org/10.1016/0277-9536(89)90026-9	Nigeria	Nigeria	“This paper reviews some studies done on the psychological aspects of albinism. Studies on the intellectual ability of albinos produce equivocal results.” (p. 1129)	Case Study
13	Estrada-Hernández, N. & Harper, D.C. (2007). Research on psychological and personal aspects of albinism: A critical review. *Rehabilitation Psychology*, *52*(3), 263–271. https://doi.org/10.1037/0090-5550.52.3.263	US	Global	“The authors conducted a critical review of the research literature, examining factors associated with adaptation to the albinism condition.” (p. 263)	Critical Review

14	Heinmiller, L. J., Holleschau, A., & Summers, C. G. (2016). Concordance of visual and structural features between siblings with albinism. *Journal the American Association for Pediatric Ophthalmology and Strabismus, 20*(1), 34–36. https://doi.org/10.1016/j.jaapos.2015.10.009	US	US	"To evaluate similarities and differences in visual function and ocular structure between siblings with albinism." (p. 34)	Quantitative
15	Huang, M., Chen, L., Hung, S. & Puthussery, S. (2022). Women's experiences of living with albinism in Taiwan and perspectives on reproductive decision making: A qualitative study. *Disability & Society, 37*(6), 916-932. https://doi.org/10.1080/09687599.2020.1867071	Taiwan	Taiwan	"This study aimed to explore lived experiences of women with Albinism and to understand their perspectives on reproductive decision making." (p. 916)	Qualitative
16	International Federation of Red Cross and Red Crescent Societies. (2009). *Through albino eyes: The plight of albino people in Africa's Great Lakes region and a Red Cross*	unknown	Tanzania	This provides reports about the human rights violations on PWA, with reports of attacks in the Great Lakes regions, Tanzania.	Discussion

	response. https://actiononalbinism.org/api/files/1532538047872yn2bimyf2vn3zo050jbw97ldi.pdf				
17	Ishaq, M., Niazi, M. K., Khan, M. S., & Nadeem, Y. (2015). Partial Oculocutaneous Albinism: Two siblings with features of both Hermansky Pudlak and Waardenburg's Syndrome. *Journal of the College of Physicians and Surgeons--Pakistan*. *25*, S43–S44.	Pakistan	Pakistan	"Two siblings of partial oculocutaneous albinism with features of both HPS and WS were identified and reported." (p. 43)	Case Study
18	Javangwe G. & Mukondyo, R. (2012). A comparison of the interactive play behaviours between children with albinism and their siblings and children without albinism and their non-albino siblings, *Early Child Development and Care*, *182*(12), 1593-1610. https://doi.org/10.1080/03004430.2011.630074	Zimbabwe	Zimbabwe	"The study explored the nature of the interactive play behaviours of children with albinism and children without albinism and compared the interactive behaviours of both children with albinism and children without albinism." (p. 1593)	Quantitative
19	Kim K. S. (1999). Case report: A Systems approach to genetic counseling for	US	US	"Case of a girl with albinism born to a couple from India [migrated to the US] will be used to	Case study

	albinism. *Journal of Genetic Counseling, 8*(1), 47–54. https://doi.org/10.1023/A:1022834620511			discuss how a systems approach might be useful in a genetic counseling setting.” (p. 47)	
20	Kromberg, J.G.R. (2018b). Psychosocial and cultural aspects of albinism. In J.G.R. Kromberg & P. Manga, *Albinism in Africa: Historical, geographic, medical, genetic, and psychosocial aspects* (pp. 172-198). Academic Press.	South Africa	Africa	“The topics to be discussed will include the psychosocial impact on the family of the birth of a child with albinism and the associated maternal- and paternal-infant bonding. Then the adjustment of affected children and adults in their home and community settings will be investigated, and the extent of the anxiety and the stigmatization they experience will be examined.” (p. 172)	discussion
21	Lund P. M. (2001). Health and education of children with albinism in Zimbabwe. *Health Education Research, 16*(1), 1–7. https://doi.org/10.1093/her/16.1.1	UK	Zimbabwe	“This article describes the responses to a self-report questionnaire covering health, social, and educational aspects completed by 138 school children with albinism living in a rural area in Zimbabwe.” (p. 1)	Qualitative

22	Lynch, P., Lund, P. & Massah, B. (2014). Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi. *International Journal of Educational Development, 39,* 226-234. https://doi.org/10.1016/j.ijedudev.2014.07.002	UK (1,2), Malawi (3)	Malawi	"In a participatory study, consultations with educational professionals, children with albinism and their families documented the barriers to full educational access and revealed low-cost strategies that could be implemented in mainstream schools, to minimise the effect of the visual impairment associated with albinism." (p. 226)	Qualitative
23	Lund, P., Massah, B. & Lynch, P. (2015). *Barriers to access: factors limiting full participation of children with albinism at school in northern Malawi: Part 2.* https://pureportal.coventry.ac.uk/en/publications/barriers-to-access-factors-limiting-full-participation-of-childre-3	UK	Malawi	exploring the educational experiences of children with albinism in Malawi	Qualitative

24	Keshav, B. R., Mohammed, M. J., & Mahmood, N. (2010). Oculocutaneous Albinism associated with Axenfeld's Anomaly: Three case reports. *Sultan Qaboos University Medical Journal*, *10*(1), 111–113.	Oman	Oman	“We present cases of three siblings of a family with identical presentation suggesting that this association may be more than just a coincidence.” (p. 111)	Case Study
25	Mazibuko, N. & Kromberg, J.G.R. (2018). A personal perspective. Living with albinism. In J.G.R. Kromberg & P. Manga, *Albinism in Africa: Historical, geographic, medical, genetic, and psychosocial aspects* (pp. 295-305). Academic Press.	South Africa	Africa	The second youngest of the Ngwenya family is Nomasonto Grace Ngwenya, and it is her life story and perspective that is the topic of this chapter. She’s a person with albinism in South Africa. She was an educator and founder of the Albinism Society of South Africa.	Case Study
26	Olagunju, A. (2019). *‘Being different’: realities of life experiences as constructed by persons with albinism in Nigeria* [Dissertation, University of Chester]. https://chesterrep.openrepository.com/handle/10034/623072	England	Nigeria	“This research aimed to understand how the realities of being a PWA in Nigeria could be conceptualised based on their life experiences to develop a substantive theory of their social wellbeing status.” (p. 10)	Qualitative

27	Summers, C. G., Creel, D., Townsend, D., & King, R. A. (1991). Variable expression of vision in sibs with albinism. *American Journal of Medical Genetics*, *40*(3), 327–331. https://doi.org/10.1002/ajmg.1320400316	US	US	“Reporting 2 brothers with OCA and markedly different visual acuity.” (p. 327)	Case Study
28	Tsuji, T., & Saito, T. (1978). Multiple naevocellular naevi in brothers with albinism. *The British Journal of Dermatology*, *98*(6), 685–692. https://doi.org/10.1111/j.1365-2133.1978.tb03589.x	Japan	Japan	Multiple naevocellular naevi occurring in two albino brothers are described. The light and electron microscopic findings of the naevi are described, and the nature of the pigment discussed.	Case Study
29	UNICEF. (2011). *Study on children with albinism in Nigeria: Knowledge, attitude and practices.* https://albinofoundation.org/wp-content/uploads/2017/03/UNICEF-Report-on-Children-with-albinism-in-Nigeria.pdf	International	Nigeria	“The survey seeks to answer the following questions: i. What is albinism and what are the critical stigmas that people usually associate with albinos and albinism in Nigeria? ii. What are the various types or forms of discrimination against children with albinism? iii. To what extent are children with	Mixed

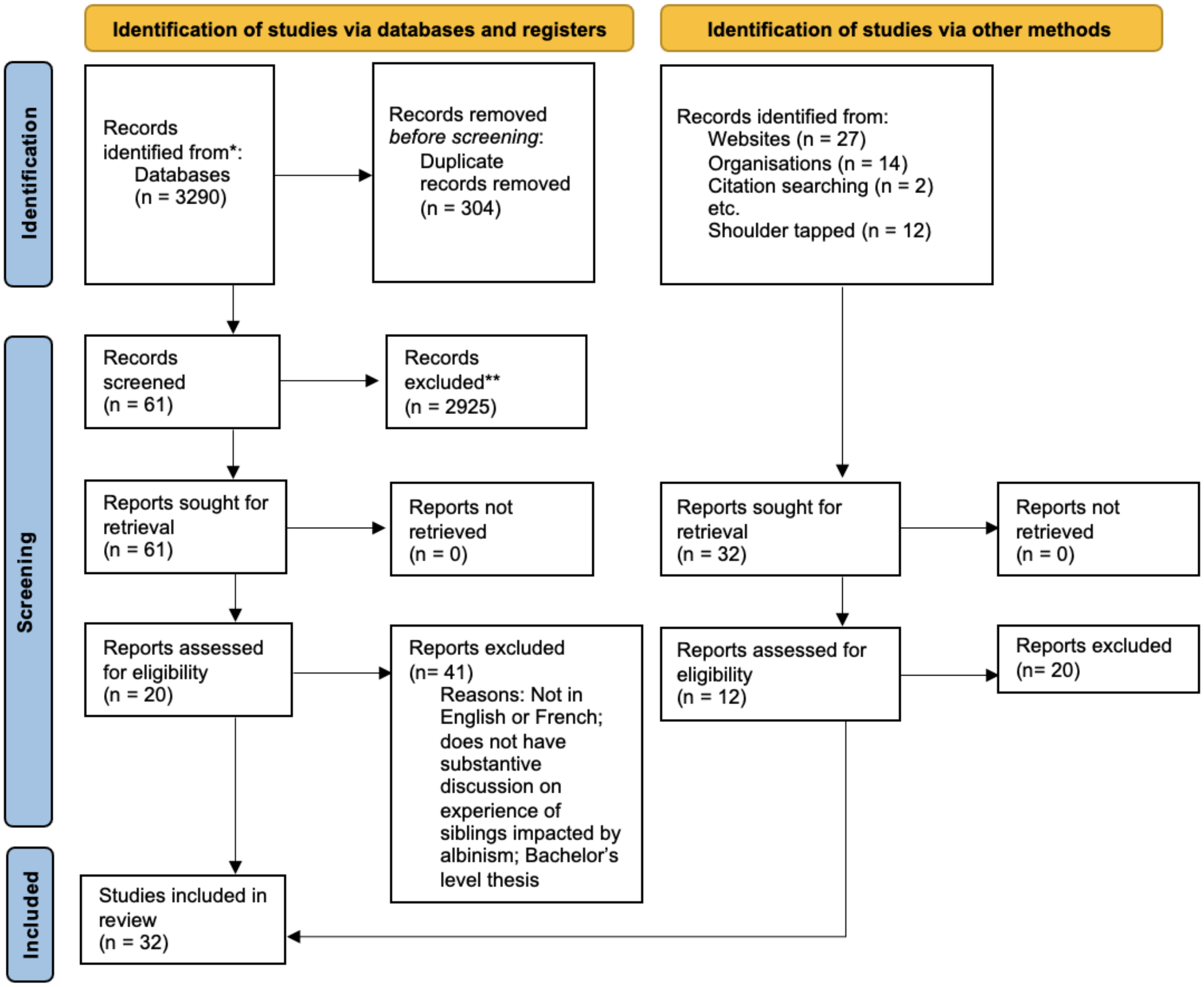
				albinism having access to health and educational facilities, information, employment, financial assistance and social services in Nigeria? iv. What are the cultural and societal relationships that lead to stereotyping and ostracizing (shunning) children with albinism in schools and communities? v. What are the other factors/variables that enable the formulation and implementation of programmes and policies to assist the full integration of children with albinism in schools and in the society at large? vi. How many children with albinism are living with cancer or are showing early signs of cancer?" (p. 3)	

30	Ünsel Bolat, G. (2020). Case report: diagnosis and treatment of attention deficit hyperactivity disorder and autism spectrum disorder in patients diagnosed with oculocutaneous albinism. *Neurocase*, *26*(6), 360–363. https://doi.org/10.1080/13554794.2020.1853174	Turkey	Turkey	"We report two siblings with OCA who presented with symptoms of autism spectrum disorder and attention deficit hyperactivity disorder (ADHD). Ocular side effects occurred after methylphenidate (MPH) treatment in the patient with ADHD and OCA." (p.360)	Case study
31	Valente, A., & Caleffi, E. (2010). Two cases of burns in children from French Guinea with oculocutaneous albinism. *Annals of Burns and Fire Disasters*, *23*(3), 146–150.	Italy	Italy	"In this article we examine two cases of two children that came to our attention in August 2009, a sister and brother affected by oculocutaneous albinism type 1 (negative tyrosinase)." (p. 146)	Case Study
32	Yahalom, C., Sharon, D., Dalia, E., Simhon, S. B., Shemesh, E., & Blumenfeld, A. (2015). Combined occurrence of autosomal dominant aniridia and autosomal recessive albinism in several members of a family. *Ophthalmic Genetics*, *36*(2), 175–179. https://doi.org/10.3	Israel	Unknown	"To characterize clinical and genetic aspects of a family with a unique combination of two hereditary blinding eye diseases." (p. 175)	Case Study

	109/13816810.2015.1005318				

Appendix C

PRISMA Diagram



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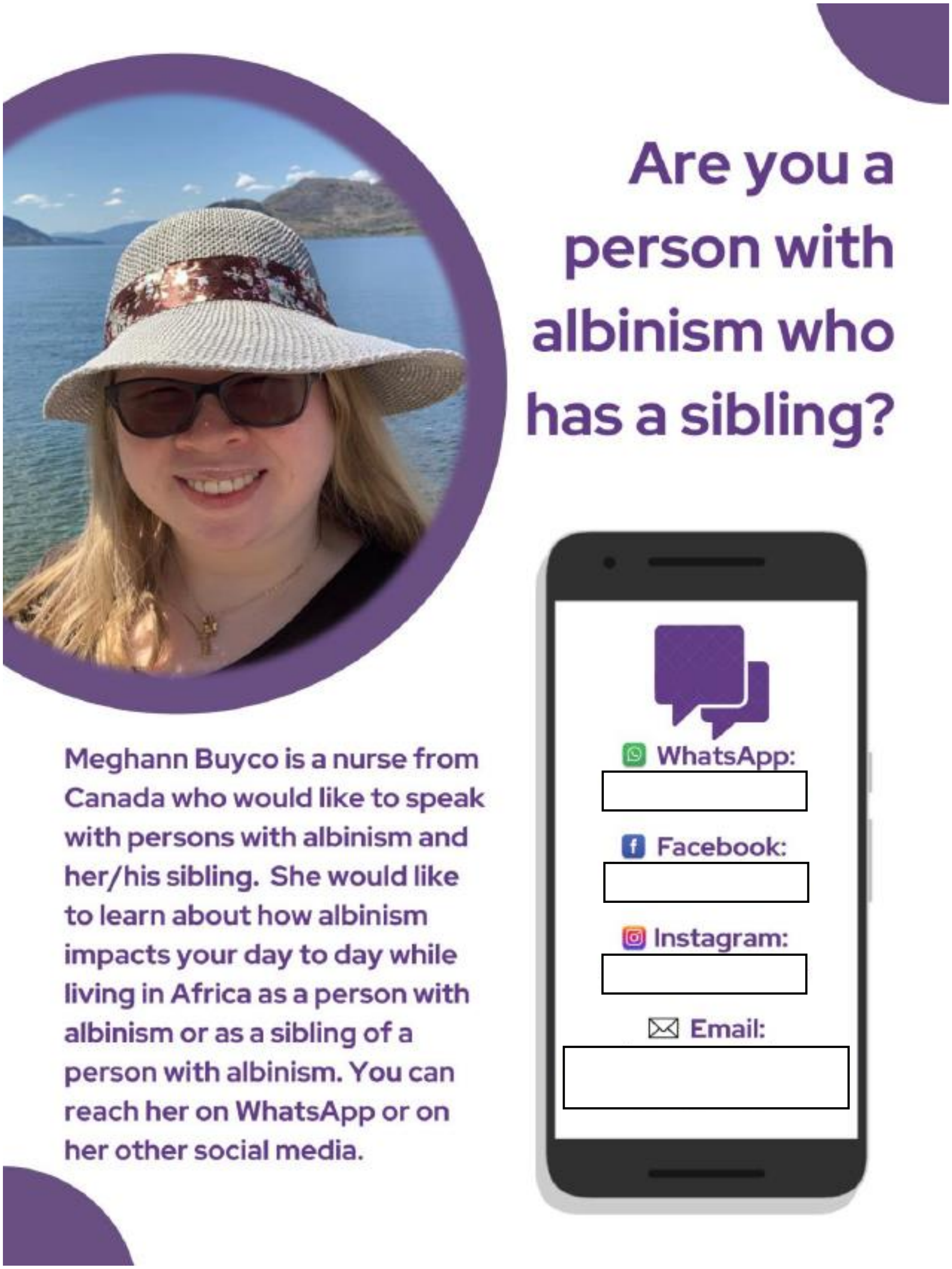
Appendix D

Virtual Flyer



Are you a person with albinism who has a sibling?

Meghann Buyco is a nurse from Canada who would like to speak with persons with albinism and her/his sibling. She would like to learn about how albinism impacts your day to day while living in Africa as a person with albinism or as a sibling of a person with albinism. You can reach her on WhatsApp or on her other social media.

WhatsApp:

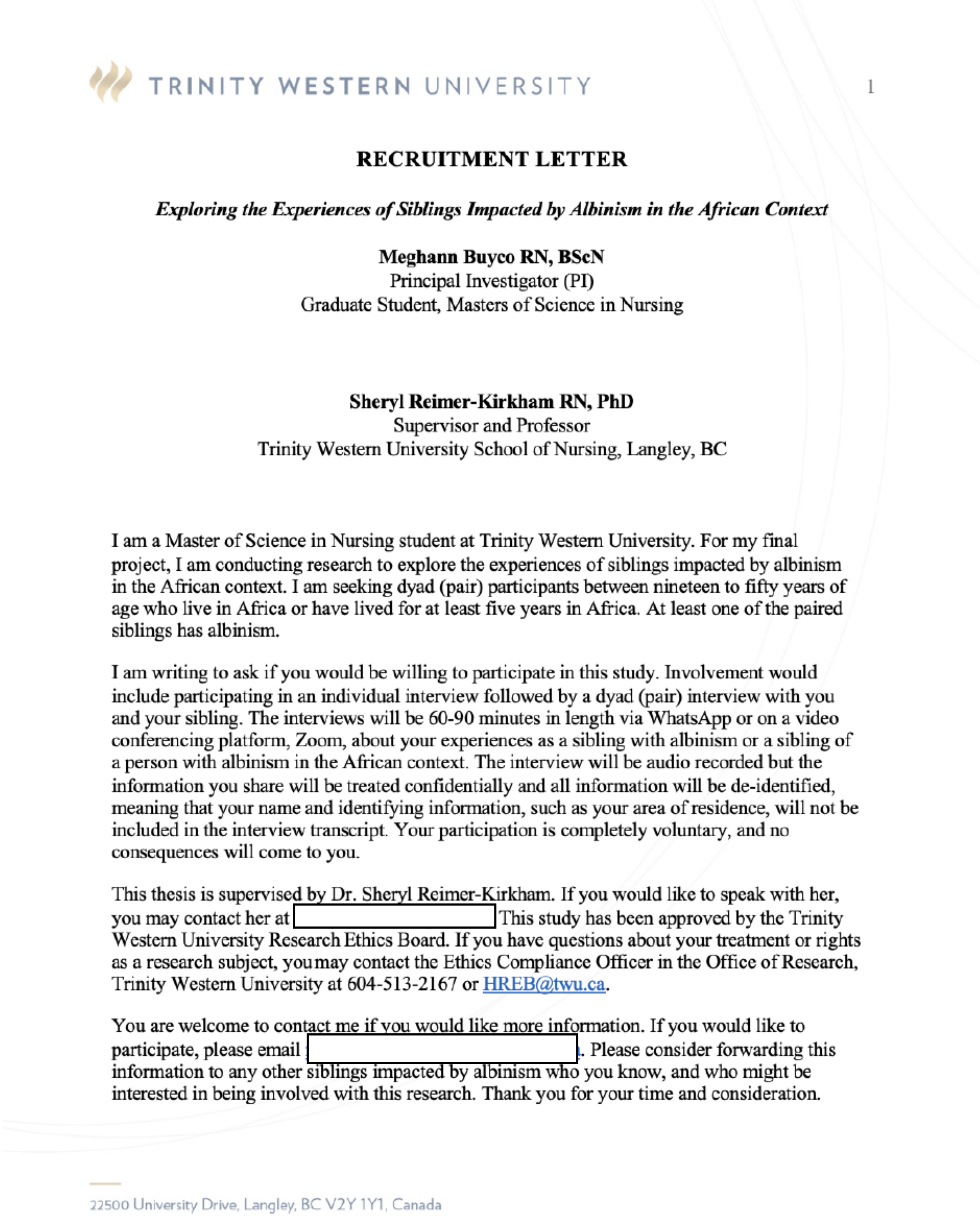
Facebook:

Instagram:

Email:

Appendix E

Recruitment Letter



TRINITY WESTERN UNIVERSITY 1

RECRUITMENT LETTER

Exploring the Experiences of Siblings Impacted by Albinism in the African Context

Meghann Buyco RN, BScN
Principal Investigator (PI)
Graduate Student, Masters of Science in Nursing

Sheryl Reimer-Kirkham RN, PhD
Supervisor and Professor
Trinity Western University School of Nursing, Langley, BC

I am a Master of Science in Nursing student at Trinity Western University. For my final project, I am conducting research to explore the experiences of siblings impacted by albinism in the African context. I am seeking dyad (pair) participants between nineteen to fifty years of age who live in Africa or have lived for at least five years in Africa. At least one of the paired siblings has albinism.

I am writing to ask if you would be willing to participate in this study. Involvement would include participating in an individual interview followed by a dyad (pair) interview with you and your sibling. The interviews will be 60-90 minutes in length via WhatsApp or on a video conferencing platform, Zoom, about your experiences as a sibling with albinism or a sibling of a person with albinism in the African context. The interview will be audio recorded but the information you share will be treated confidentially and all information will be de-identified, meaning that your name and identifying information, such as your area of residence, will not be included in the interview transcript. Your participation is completely voluntary, and no consequences will come to you.

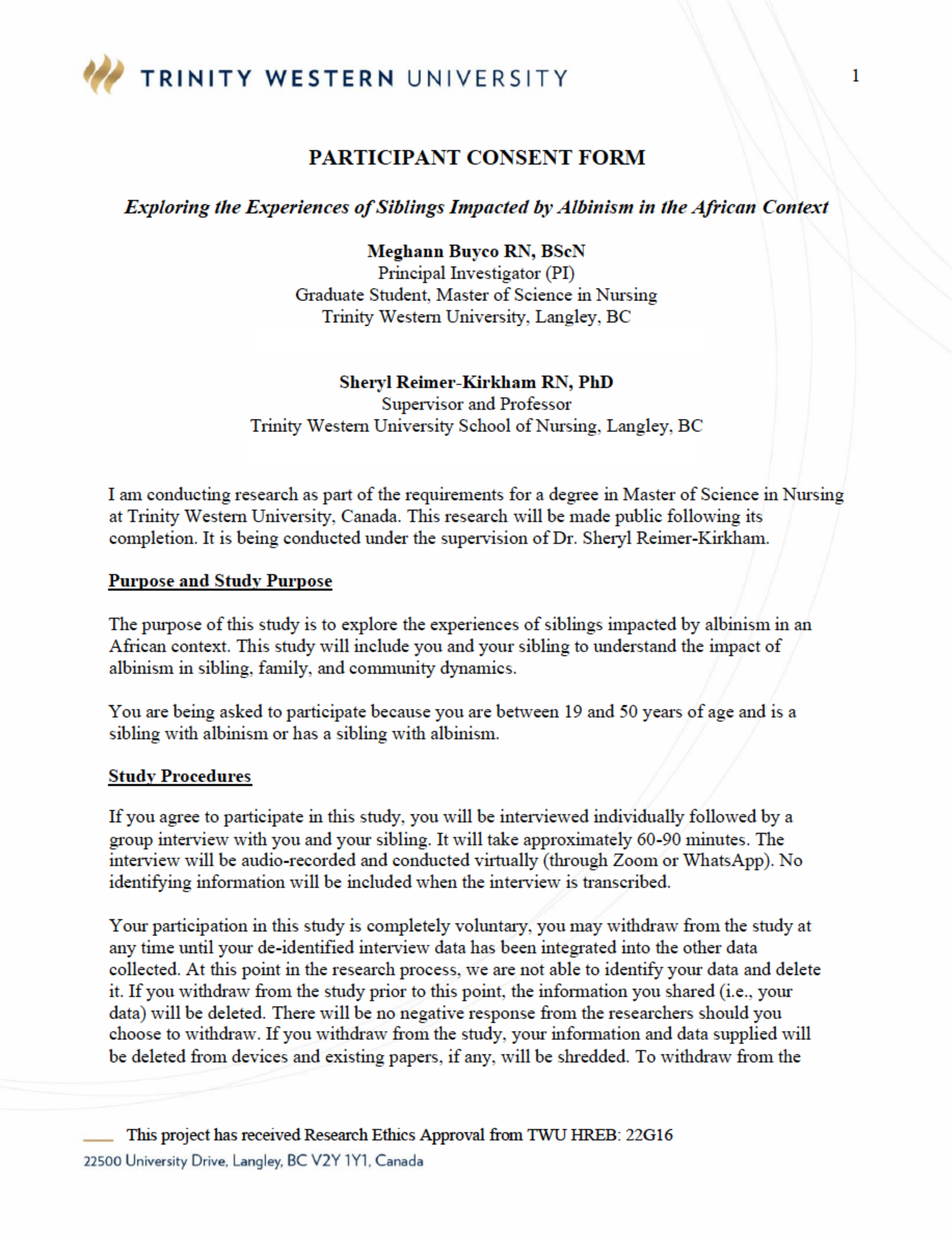
This thesis is supervised by Dr. Sheryl Reimer-Kirkham. If you would like to speak with her, you may contact her at [redacted] This study has been approved by the Trinity Western University Research Ethics Board. If you have questions about your treatment or rights as a research subject, you may contact the Ethics Compliance Officer in the Office of Research, Trinity Western University at 604-513-2167 or HREB@twu.ca.

You are welcome to contact me if you would like more information. If you would like to participate, please email [redacted]. Please consider forwarding this information to any other siblings impacted by albinism who you know, and who might be interested in being involved with this research. Thank you for your time and consideration.

22500 University Drive, Langley, BC V2Y 1Y1, Canada

Appendix F

Consent Form



TRINITY WESTERN UNIVERSITY

PARTICIPANT CONSENT FORM

Exploring the Experiences of Siblings Impacted by Albinism in the African Context

Meghann Buyco RN, BScN
Principal Investigator (PI)
Graduate Student, Master of Science in Nursing
Trinity Western University, Langley, BC

Sheryl Reimer-Kirkham RN, PhD
Supervisor and Professor
Trinity Western University School of Nursing, Langley, BC

I am conducting research as part of the requirements for a degree in Master of Science in Nursing at Trinity Western University, Canada. This research will be made public following its completion. It is being conducted under the supervision of Dr. Sheryl Reimer-Kirkham.

Purpose and Study Purpose

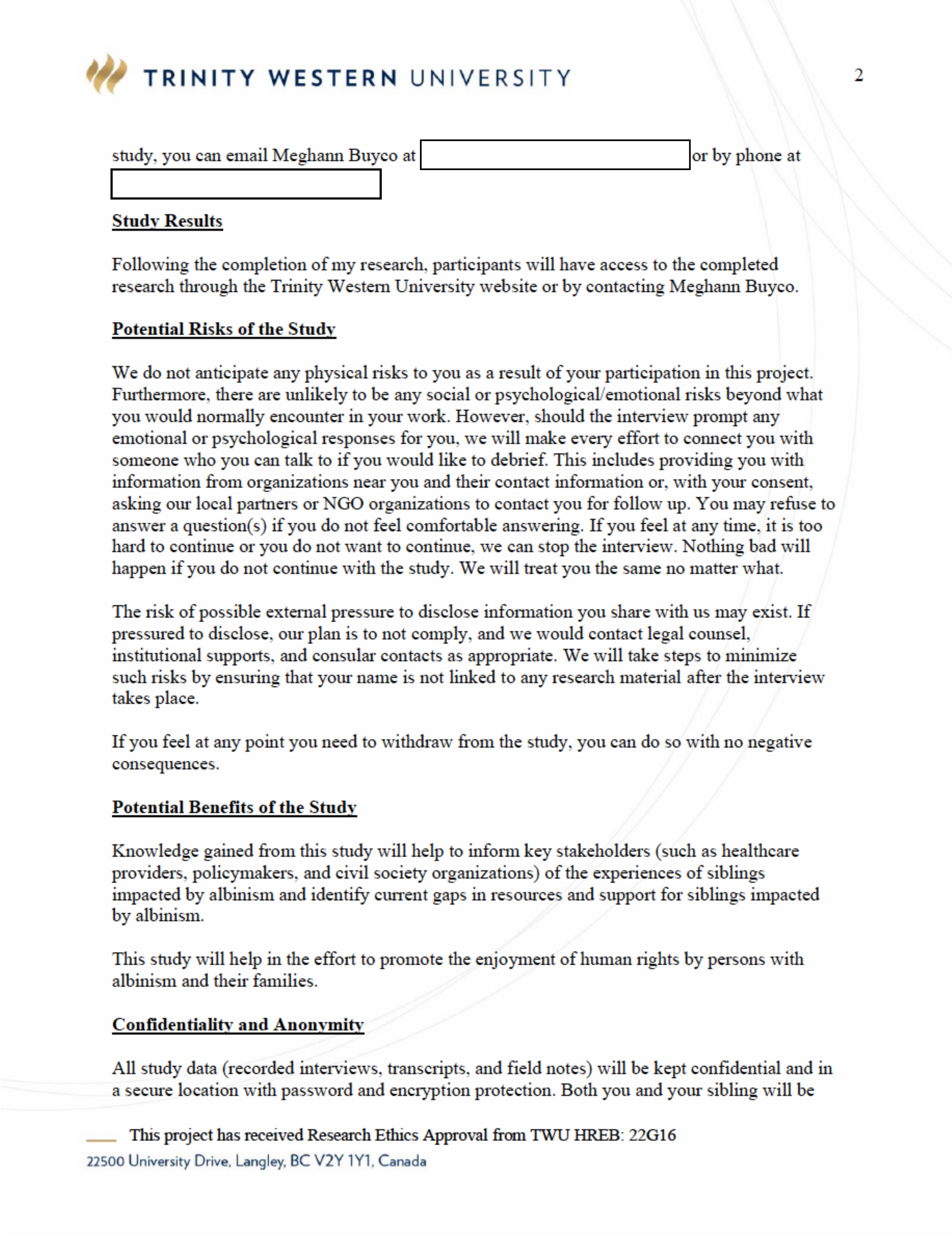
The purpose of this study is to explore the experiences of siblings impacted by albinism in an African context. This study will include you and your sibling to understand the impact of albinism in sibling, family, and community dynamics.

You are being asked to participate because you are between 19 and 50 years of age and is a sibling with albinism or has a sibling with albinism.

Study Procedures

If you agree to participate in this study, you will be interviewed individually followed by a group interview with you and your sibling. It will take approximately 60-90 minutes. The interview will be audio-recorded and conducted virtually (through Zoom or WhatsApp). No identifying information will be included when the interview is transcribed.

Your participation in this study is completely voluntary, you may withdraw from the study at any time until your de-identified interview data has been integrated into the other data collected. At this point in the research process, we are not able to identify your data and delete it. If you withdraw from the study prior to this point, the information you shared (i.e., your data) will be deleted. There will be no negative response from the researchers should you choose to withdraw. If you withdraw from the study, your information and data supplied will be deleted from devices and existing papers, if any, will be shredded. To withdraw from the



study, you can email Meghann Buyco at [redacted] or by phone at [redacted]

Study Results

Following the completion of my research, participants will have access to the completed research through the Trinity Western University website or by contacting Meghann Buyco.

Potential Risks of the Study

We do not anticipate any physical risks to you as a result of your participation in this project. Furthermore, there are unlikely to be any social or psychological/emotional risks beyond what you would normally encounter in your work. However, should the interview prompt any emotional or psychological responses for you, we will make every effort to connect you with someone who you can talk to if you would like to debrief. This includes providing you with information from organizations near you and their contact information or, with your consent, asking our local partners or NGO organizations to contact you for follow up. You may refuse to answer a question(s) if you do not feel comfortable answering. If you feel at any time, it is too hard to continue or you do not want to continue, we can stop the interview. Nothing bad will happen if you do not continue with the study. We will treat you the same no matter what.

The risk of possible external pressure to disclose information you share with us may exist. If pressured to disclose, our plan is to not comply, and we would contact legal counsel, institutional supports, and consular contacts as appropriate. We will take steps to minimize such risks by ensuring that your name is not linked to any research material after the interview takes place.

If you feel at any point you need to withdraw from the study, you can do so with no negative consequences.

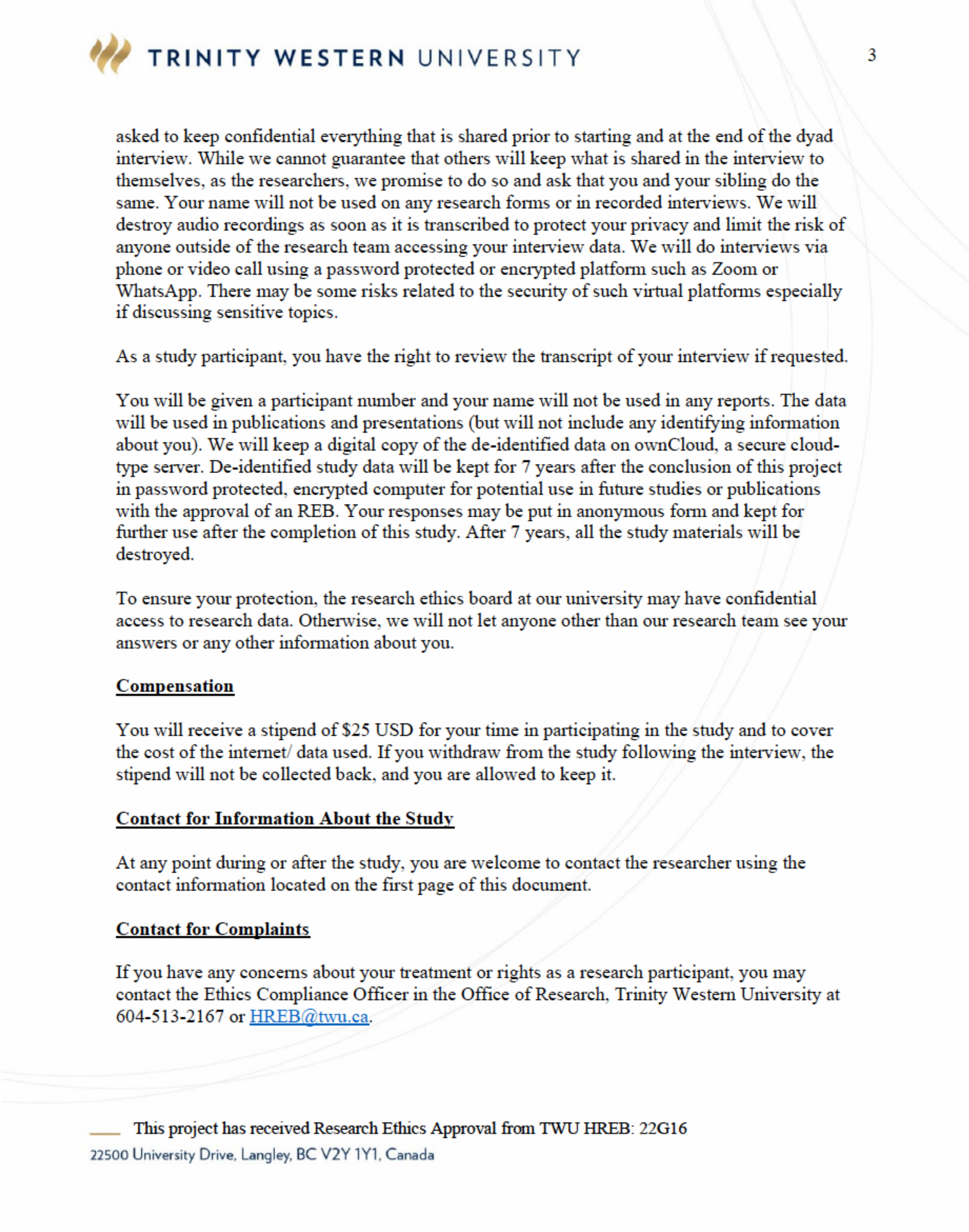
Potential Benefits of the Study

Knowledge gained from this study will help to inform key stakeholders (such as healthcare providers, policymakers, and civil society organizations) of the experiences of siblings impacted by albinism and identify current gaps in resources and support for siblings impacted by albinism.

This study will help in the effort to promote the enjoyment of human rights by persons with albinism and their families.

Confidentiality and Anonymity

All study data (recorded interviews, transcripts, and field notes) will be kept confidential and in a secure location with password and encryption protection. Both you and your sibling will be



asked to keep confidential everything that is shared prior to starting and at the end of the dyad interview. While we cannot guarantee that others will keep what is shared in the interview to themselves, as the researchers, we promise to do so and ask that you and your sibling do the same. Your name will not be used on any research forms or in recorded interviews. We will destroy audio recordings as soon as it is transcribed to protect your privacy and limit the risk of anyone outside of the research team accessing your interview data. We will do interviews via phone or video call using a password protected or encrypted platform such as Zoom or WhatsApp. There may be some risks related to the security of such virtual platforms especially if discussing sensitive topics.

As a study participant, you have the right to review the transcript of your interview if requested.

You will be given a participant number and your name will not be used in any reports. The data will be used in publications and presentations (but will not include any identifying information about you). We will keep a digital copy of the de-identified data on ownCloud, a secure cloud-type server. De-identified study data will be kept for 7 years after the conclusion of this project in password protected, encrypted computer for potential use in future studies or publications with the approval of an REB. Your responses may be put in anonymous form and kept for further use after the completion of this study. After 7 years, all the study materials will be destroyed.

To ensure your protection, the research ethics board at our university may have confidential access to research data. Otherwise, we will not let anyone other than our research team see your answers or any other information about you.

Compensation

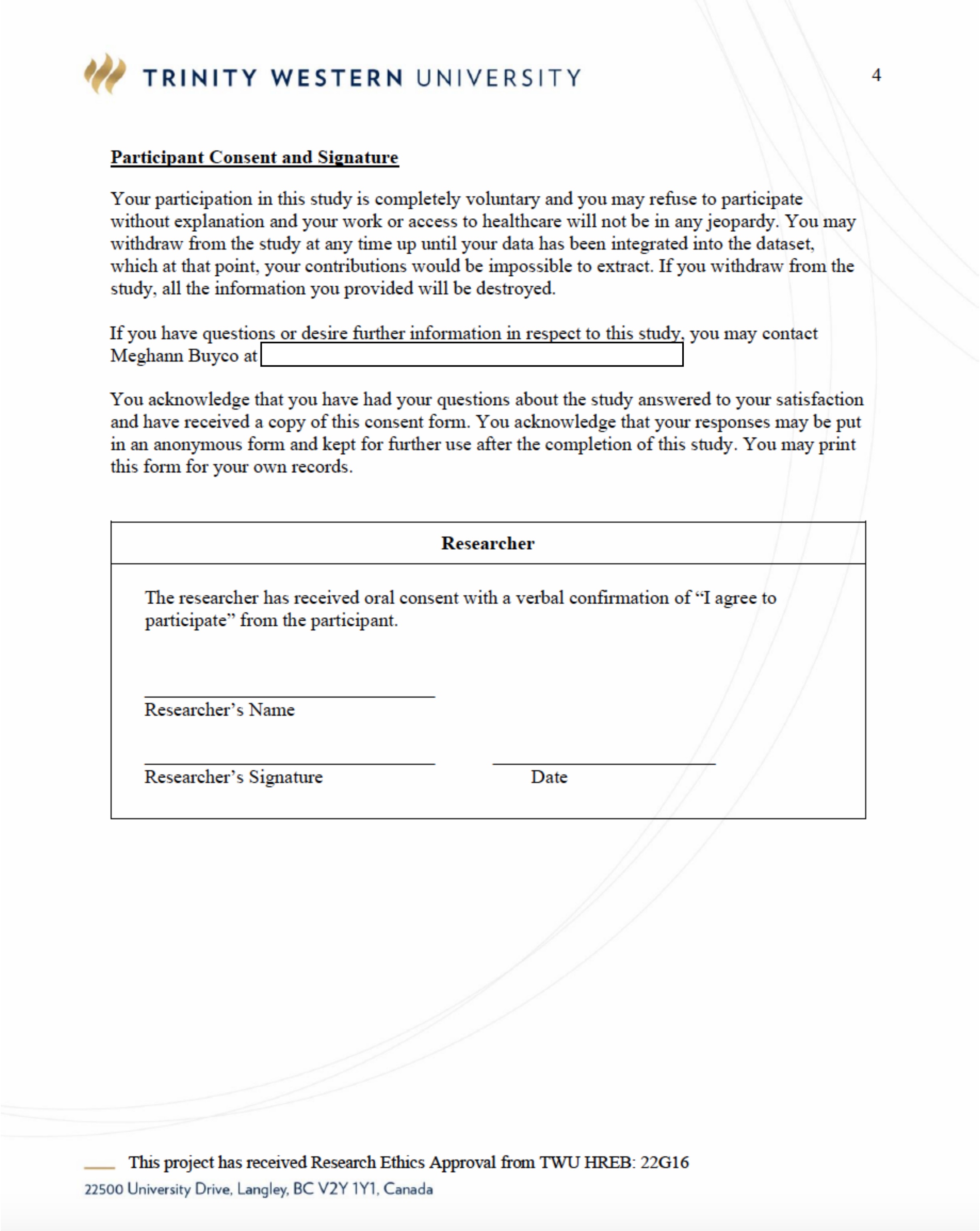
You will receive a stipend of $25 USD for your time in participating in the study and to cover the cost of the internet/ data used. If you withdraw from the study following the interview, the stipend will not be collected back, and you are allowed to keep it.

Contact for Information About the Study

At any point during or after the study, you are welcome to contact the researcher using the contact information located on the first page of this document.

Contact for Complaints

If you have any concerns about your treatment or rights as a research participant, you may contact the Ethics Compliance Officer in the Office of Research, Trinity Western University at 604-513-2167 or HREB@twu.ca.



Participant Consent and Signature

Your participation in this study is completely voluntary and you may refuse to participate without explanation and your work or access to healthcare will not be in any jeopardy. You may withdraw from the study at any time up until your data has been integrated into the dataset, which at that point, your contributions would be impossible to extract. If you withdraw from the study, all the information you provided will be destroyed.

If you have questions or desire further information in respect to this study, you may contact Meghann Buyco at

You acknowledge that you have had your questions about the study answered to your satisfaction and have received a copy of this consent form. You acknowledge that your responses may be put in an anonymous form and kept for further use after the completion of this study. You may print this form for your own records.

Researcher

The researcher has received oral consent with a verbal confirmation of "I agree to participate" from the participant.

Researcher's Name

Researcher's Signature

Date

Appendix G

Interview Guides

Sibling with Albinism

1. Who are in your family?
2. What is it like growing up with albinism?

Intra-family

3. How would you describe the relationship (interactions; roles; responsibilities) you have with your sibling(s)?
    a. How do you describe your interactions?
    b. What roles did each of you and your sibling play in the family? What responsibilities did you have?
4. Have you felt that your parents treated you differently than your sibling because you have albinism? If so, how?
    a. Have you ever felt like you have been treated differently by your sibling(s) because you had albinism? If so, how?
5. What were your main worries as a person with albinism?

Extra-family

6. Community: Can you describe the community you lived in as a family?
    a. How do you describe your place as a family (with your siblings) in your community? When you were growing up? Now?
    b. How were you perceived by the community?
7. Safety & Stigma: Have you ever felt that you or your siblings are not safe? Have you or your siblings felt that you have been treated (in the community) differently because you had albinism?
8. Access: What were your experiences accessing health services?
    a. Health-related knowledge?
    b. Sunscreen or skin screening?
    c. Vision care and prescription lenses?
9. How have cultural and spiritual beliefs practices and faith communities influenced your family? [Listen for stigmatized belief; faith community support…]
10. What resources were provided for you as a person with albinism? In school? Peer support in the community?
11. I am interested in a family-centred approach which takes into account each member of the family to set up goals, strengthen their capacities, and make decisions together. What do you think would help support families impacted by albinism?

Sibling without albinism

1. Who are in your family?
2. What is it like growing up with a sibling with albinism?
    a. How does having a sibling with a disability impact your day-to-day?

Intra-Family

3. How would you describe the relationship (interactions; roles; responsibilities) you have with your sibling(s)?
    a. How do you describe your interactions?
    b. What roles did each of you and your sibling play in the family? What responsibilities did you have?
4. How did your parents explain to you about your sibling's condition?
5. Have you felt that your parents have treated you and/or your sibling differently because your brother/sister has albinism?
6. What were your main worries as a sibling of a person with albinism?

Extra-Family

7. Community: Can you describe the community you lived in as a family?
    a. How do you describe your place as a family (with your siblings) in your community? When you were growing up? Now?
    b. How were your family perceived by the community?
8. Safety and stigma: Safety & Stigma: Have you ever felt that you or your siblings are not safe? Have you or your siblings felt that you have been treated (in the community) differently because you had a sibling with albinism?
9. Healthcare access: What were your experiences accessing health services?
    a. Were you provided with health-related knowledge from healthcare providers like doctors or nurses? Counselling? Mental health?
    b. Were you provided support/ services by healthcare providers as a person with siblings with albinism?
10. How have cultural and spiritual beliefs practices and faith communities influenced your family? [Listen for stigmatized belief; faith community support]
11. What were the resources that was provided for you as a sibling of a person with albinism? In school? Peer support in the community?
12. I am interested in a family-centred approach which takes into account each member of the family to set up goals, strengthen their capacities, and to make decisions together. What do you think would help support families impacted by albinism?

Dyad Interview

1. How do your family and siblings contribute to who you are today? (identity)
2. What family values contribute to your resilience and well-being?
3. How have you (past/present) spent your time together as siblings?
4. What family traditions or practices (celebrations, ceremonies) did you partake in together?
5. Could you provide some examples of how you support each other? (Growing up, as adults)
6. How do you deal with disagreements?
7. Anything else you would like me to know?

Appendix H

Observation Guides

Individual Interviews

Mode of Interview (Zoom, WhatsApp):

Setting for researcher:

Setting of the participant (what is seen and heard in the background; are there people around; How is the participant situated):

What did the participants have to do to be in the interview today?

Note the changes in the tone and volume of voice, posture, and behaviour. Were there times it was uncomfortable for the participant? Were there times the participant was smiling or laughing?

Other comments:

Dyad Interviews

Mode of Interview (Zoom, WhatsApp):

Setting for researcher:

Setting of the participants (what is seen and heard in the background; are there people around):

How are participants situated?

What can be observed in the attitude and behaviour of the dyad (ie. How close are they sitting? How do they interact with one another? Do they interrupt or add to the statements of the other?):

Other comments:

Appendix I

Demographic Form

Code		**Sibling Code**	
City, Country		**Interview Date**	
Interview Location		**Interview Time**	
Urban/ Rural			

Age range:

☐ 18-20 ☐ 21-30 ☐ 31-40 ☐ 41-50

Are you a person with albinism?

☐ Yes ☐ No

Do you have any known relative(s) with albinism?

☐ Yes ☐ No

If yes, details: ____

How many siblings do you have? How many have albinism?

____

Gender:

☐ Female ☐ Male ☐ Non-binary ☐ Transgender
☐ Other: ______ ☐ Prefer not to answer

Relationship Status:

☐ Single ☐ Married ☐ Divorced/ Separated
☐ Co-habitation ☐ Other: _______ ☐ Prefer not to answer

Education Level:

☐ Primary ☐ Secondary ☐ Bachelor’s ☐ Master’s
☐ PhD ☐ Other

Employment Status:

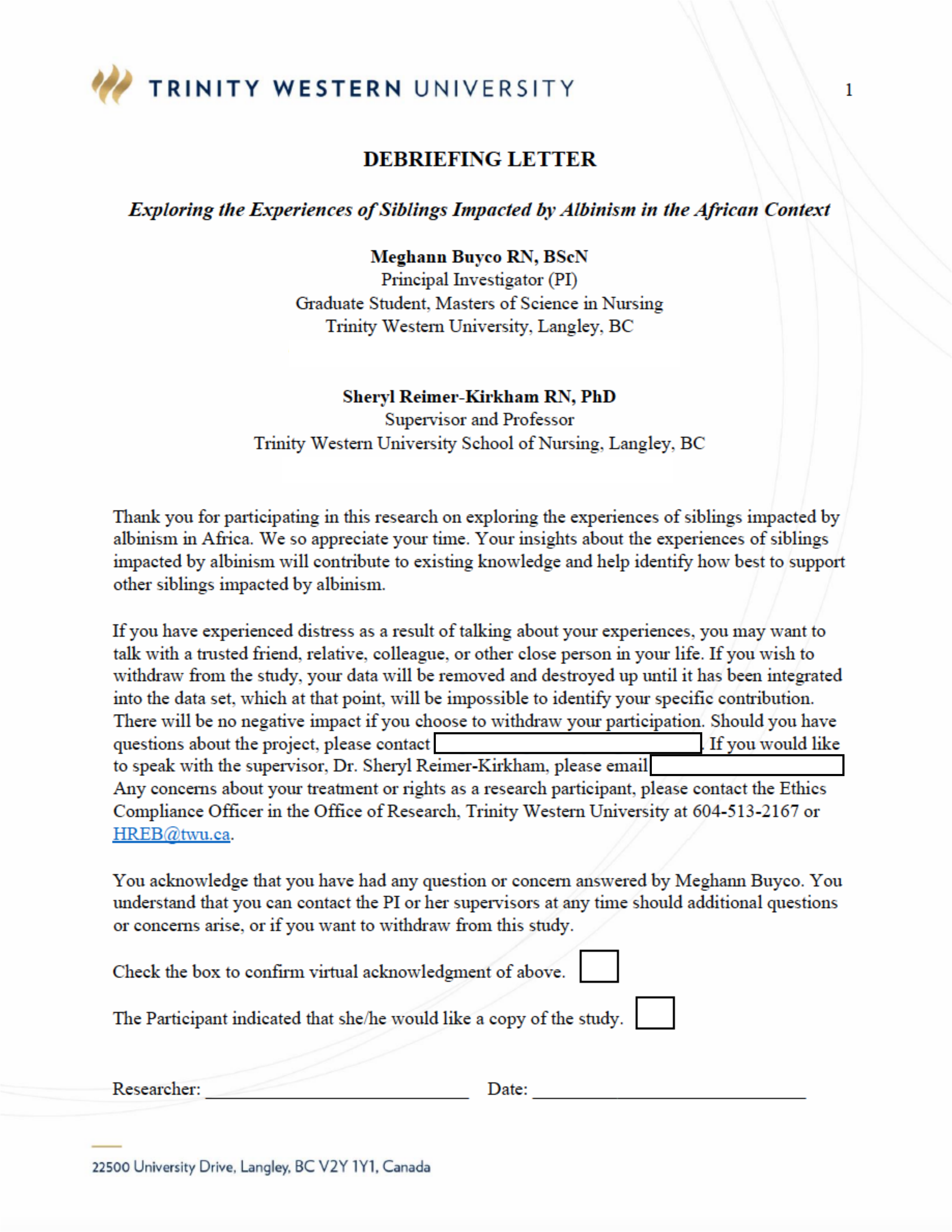
☐ Employment Income
☐ Subsistence Income
☐ Unemployed
☐ Retired
☐ Other

Ethnic/Racial Background (other national connections, migrants?):
____

Religious/Spiritual Affiliation:
____

Appendix J

Debriefing Letter



TRINITY WESTERN UNIVERSITY

DEBRIEFING LETTER

Exploring the Experiences of Siblings Impacted by Albinism in the African Context

Meghann Buyco RN, BScN
Principal Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC

Sheryl Reimer-Kirkham RN, PhD
Supervisor and Professor
Trinity Western University School of Nursing, Langley, BC

Thank you for participating in this research on exploring the experiences of siblings impacted by albinism in Africa. We so appreciate your time. Your insights about the experiences of siblings impacted by albinism will contribute to existing knowledge and help identify how best to support other siblings impacted by albinism.

If you have experienced distress as a result of talking about your experiences, you may want to talk with a trusted friend, relative, colleague, or other close person in your life. If you wish to withdraw from the study, your data will be removed and destroyed up until it has been integrated into the data set, which at that point, will be impossible to identify your specific contribution. There will be no negative impact if you choose to withdraw your participation. Should you have questions about the project, please contact [redacted]. If you would like to speak with the supervisor, Dr. Sheryl Reimer-Kirkham, please email [redacted] Any concerns about your treatment or rights as a research participant, please contact the Ethics Compliance Officer in the Office of Research, Trinity Western University at 604-513-2167 or HREB@twu.ca.

You acknowledge that you have had any question or concern answered by Meghann Buyco. You understand that you can contact the PI or her supervisors at any time should additional questions or concerns arise, or if you want to withdraw from this study.

Check the box to confirm virtual acknowledgment of above. ☐

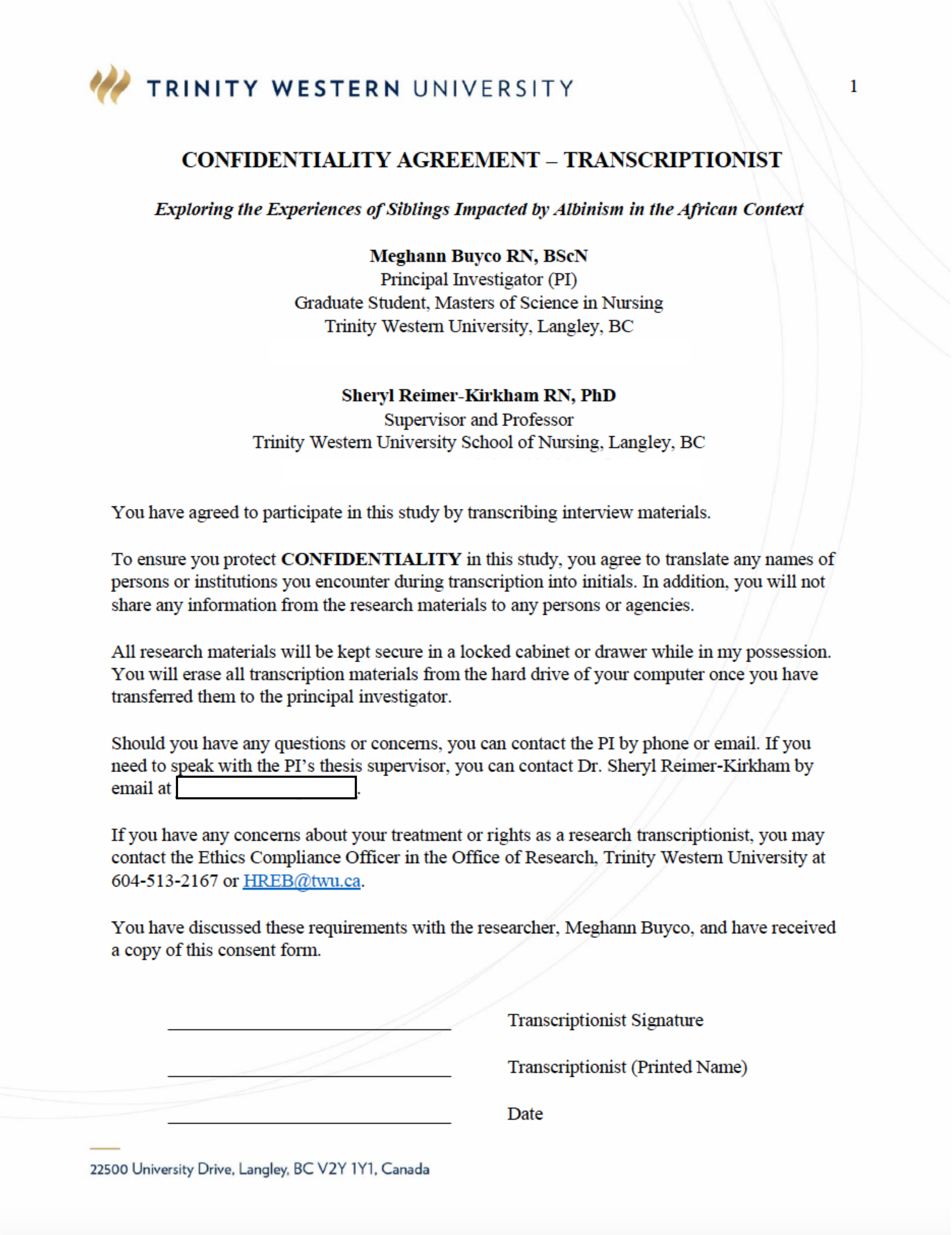
The Participant indicated that she/he would like a copy of the study. ☐

Researcher: ____________________________ Date: ______________________________

22500 University Drive, Langley, BC V2Y 1Y1, Canada

Appendix K

Confidentiality Agreement Form



TRINITY WESTERN UNIVERSITY 1

CONFIDENTIALITY AGREEMENT – TRANSCRIPTIONIST

Exploring the Experiences of Siblings Impacted by Albinism in the African Context

Meghann Buyco RN, BScN
Principal Investigator (PI)
Graduate Student, Masters of Science in Nursing
Trinity Western University, Langley, BC

Sheryl Reimer-Kirkham RN, PhD
Supervisor and Professor
Trinity Western University School of Nursing, Langley, BC

You have agreed to participate in this study by transcribing interview materials.

To ensure you protect **CONFIDENTIALITY** in this study, you agree to translate any names of persons or institutions you encounter during transcription into initials. In addition, you will not share any information from the research materials to any persons or agencies.

All research materials will be kept secure in a locked cabinet or drawer while in my possession. You will erase all transcription materials from the hard drive of your computer once you have transferred them to the principal investigator.

Should you have any questions or concerns, you can contact the PI by phone or email. If you need to speak with the PI's thesis supervisor, you can contact Dr. Sheryl Reimer-Kirkham by email at [redacted].

If you have any concerns about your treatment or rights as a research transcriptionist, you may contact the Ethics Compliance Officer in the Office of Research, Trinity Western University at 604-513-2167 or HREB@twu.ca.

You have discussed these requirements with the researcher, Meghann Buyco, and have received a copy of this consent form.

__________________________ Transcriptionist Signature

__________________________ Transcriptionist (Printed Name)

__________________________ Date

22500 University Drive, Langley, BC V2Y 1Y1, Canada

Appendix L

Codebook

- A. Growing up with albinism or with a sibling with albinism
  - A1. PWA
    - A1a. Psychological
    - A1b. Psychosocial
    - A1c. Challenges
    - A1d. Siblings both have albinism
    - A1e. PWA as human right defenders
  - A2. non-PWA
    - A2a. Response to a sibling with albinism
    - A2b. Impact of response from community
    - A2c. Concerns when having a sibling with albinism
    - A2d. Things they do differently due to albinism
    - A2e. Siblings as human rights defenders
- B. Knowledge about albinism
  - B1. In school
  - B2. NGO
  - B3. Social media
  - B4. Family or friends
- C. Interaction with siblings
  - C1. Shared experiences
  - C2. Relationship
  - C3. Sibling support
- D. Interactions with Parents
  - D1. Parenting
  - D2. Extended family
  - D3. Impact of albinism to parents
  - D4. Financial Stress
- E. Family support
  - E1. Emotional support
  - E2. Financial support
  - E3. Other
- F. Family values or culture
  - F1. Household responsibilities
- G. Community responses
  - G1. Safety concerns
  - G2. School
  - G3. Peer support
  - G4. Beliefs about albinism
  - G5. Social change
- H. Access to health and social services
- I. Recommendations for family support

Appendix M

REB Approval Letter

TRINITY
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Human Research Ethics Board
22500 University Drive
Langley, BC | V2Y 1Y1
HREB@twu.ca | 604-513-2167

HREB Certificate of Approval

To: Meghann Buyco

From: Bill Badke, HREB Co-Chair

Re: Exploring the Experiences of Siblings Impacted by Albinism in the African Context

HREB File No.: 22G16

Effective: 2022 SEP 20 Expiry: 2023 SEP 20

Approval Period: ☑ One year ☐ Three years

Approval Type: ☑ New ☐ Continuation ☐ Amendment

Certification: SmartFTP Client Digitally signed by SmartFTP Client Date: 2022.09.20 12:40:33 -07'00'

The Trinity Western University Human Research Ethics Board (TWU HREB) has reviewed and approved the research proposal and concludes that the proposed research meets appropriate standards of ethics as outlined by the current *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*.

This approval is subject to the following conditions:

1. Approval is granted for the research and purposes described in the application only.
2. Any modification to the research or research materials must be submitted to the HREB for approval before implementation.
3. Any deviations to the research or adverse events must be submitted to the HREB as soon as possible.
4. This approval is valid for the indicated approval period and a Request for Continuing Approval must be submitted and approved by the above expiry date.
5. A Final Project Report form must be submitted to the HREB when the research is complete or terminated.
6. Trinity Western University may request to review research documentation from this project to demonstrate compliance with this approved protocol and with the TWU Policy concerning Research Ethics with Human Participants.

Funded Research

Send a copy of this Certificate, with the HREB File Number in the subject line, to the Research Grants Officer at Sue.Funk@twu.ca.