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Parental perspectives on the social justice needs of children with albinism

by

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Submitted in partial fulfilment of the requirements for the degree

Magister Educationis
(Educational Psychology)

Supervisor: Dr Karien Botha

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University of Pretoria

September 2024

DECLARATION OF ORIGINALITY

I, Minishka Arnachellan (student number 17041954), declare that the dissertation titled **‘‘Parental perspectives on the social justice needs of children with albinism’’** is my original work and has not been previously submitted by me for any other degree at another university.

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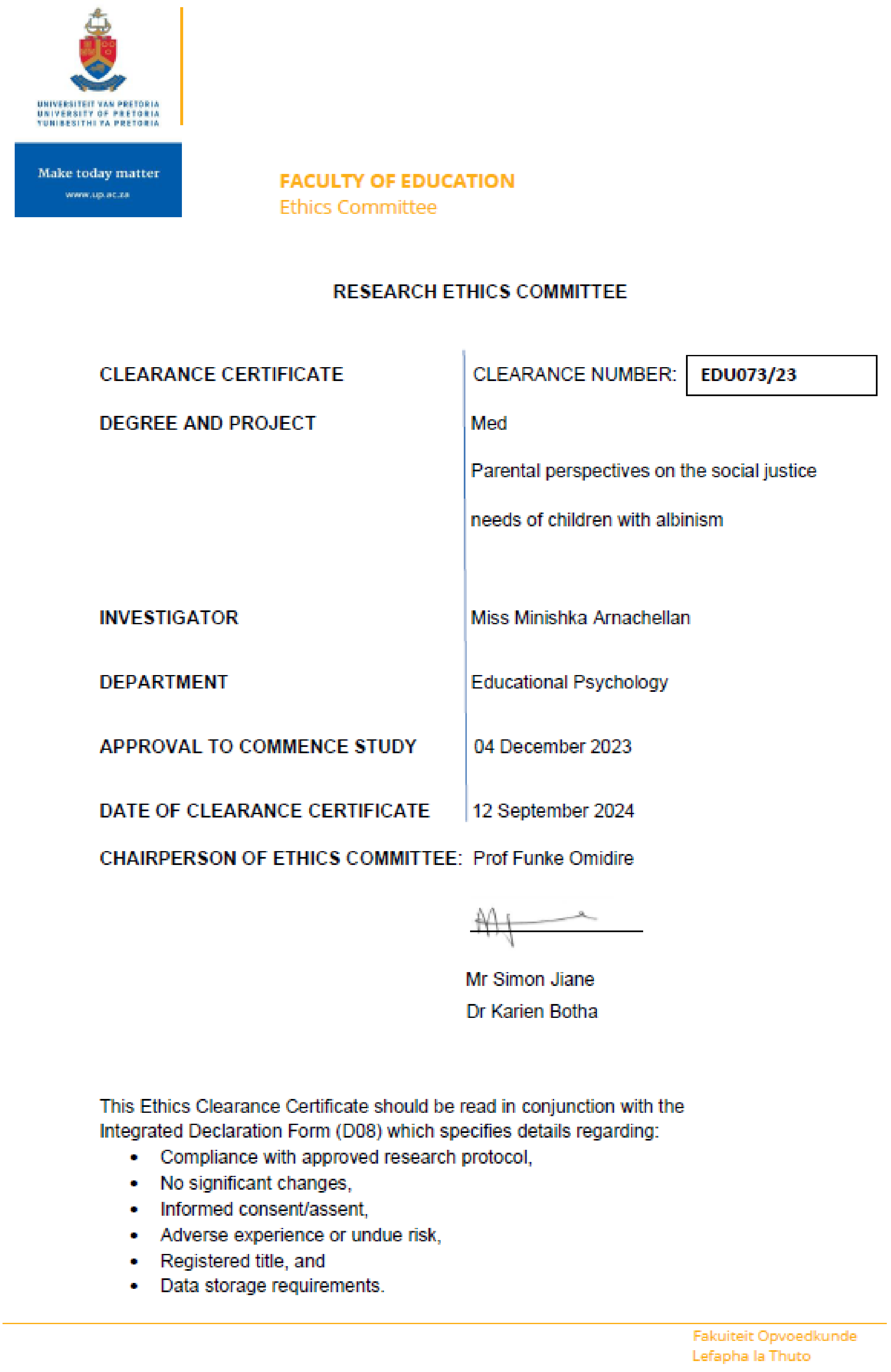

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ETHICS STATEMENT

The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, applicable ethics approval. The author declares that she has observed ethical standards required in terms of the University of Pretoria's Code of Ethics for researchers and the Policy guidelines for responsible research.

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by
Minishka Arnachellan
for the degree
MASTER OF EDUCATION (MEd) in Educational Psychology
University of Pretoria

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ABSTRACT

This study forms part of a broader research project at the Centre for Visual Impairment Studies (CVIS) at the University of Pretoria. The study focused on strengthening social justice for children with albinism with the objective of facilitating social change and equal opportunities for children with albinism as an outcome. The aim of this study of limited scope was to explore and describe parental perspectives on the social justice needs of children with albinism.

For this research study, I adopted an interpretivist paradigm and a qualitative research approach. As a guiding theoretical framework, I utilised the social model of disability. I implemented an intrinsic case study design, including Participatory Reflection and Action (PRA) activities, as well as a focus group, audio-visual recordings and a reflexive journal as methods of data generation. I purposively selected four participants, who are parents of children with albinism.

Following reflexive thematic analysis, three main themes and sub-themes emerged in relation to challenges and support requirements identified by parents of children with albinism. These are: challenges and support requirements identified by parents of children with albinism; resources required by parents to support children with albinism and parents' experiences regarding children with albinism attending mainstream schools.

Based on the findings of this study of limited scope, I can conclude that parents of children with albinism are the main sources of support for their children and that they require assistance in addressing the social justice needs of children with albinism. To this end, the parent participants highlighted specific areas in which they require support for their children with albinism and various role-players who can assist. These include the government, teachers, social workers and healthcare workers, who can provide guidance and advocate for the social justice needs of children with albinism in collaboration with parents of children with albinism. This can be achieved by increasing knowledge and awareness about albinism in attempts to reduce stigmatisations and discrimination against children with albinism. I recommend that future research focus on the role of mothers of children with albinism as primary advocates for the rights of children with albinism; and the role of communities and social networks in strengthening the social justice support for children with albinism.

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KEYWORDS

- Albinism
- Children
- Needs
- Parent
- Perspectives
- Social justice

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LIST OF ABBREVIATIONS

CVIS – Centre for Visual Impairment Studies

DBE- Department of Basic Education

IEP- Individualised education plans

PRA- Participatory reflection and action

SDG- Sustainable development goals

SGB- School governing body

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CHAPTER 1 - INTRODUCTION AND OVERVIEW OF THE STUDY

1.1 INTRODUCTION AND RATIONALE FOR UNDERTAKING THE STUDY

The current study of limited scope formed part of a broader research project within the Centre for Visual Impairment Studies (CVIS) at the University of Pretoria. The focus of the broader project is on strengthening social justice for children with albinism and is aimed at facilitating social change and equal opportunities for children with albinism as a result. Furthermore, the initial project was centred on exploring and addressing social justice challenges and needs, as well as recommendations and strategies to support equality for children with albinism. Hence in return, parental perspectives on the social justice needs of children with albinism were investigated in the current study.

In South Africa with a population of about 60.6 million, the prevalence of albinism is estimated to be around 1 in 2 000 to 4 000. Despite this number, it is a condition that remains profoundly misunderstood (Kromberg & Kerr, 2022). As a result of the lack of colour in their skin, individuals with albinism suffer adverse consequences owing to societal, cultural and economic prejudice (Nebre, 2018). Lund and Lynch (2012) assert that as a result of a deficiency of melanin in the hair, skin, and eyes of children with albinism, they tend to be deemed ‘white’ in a black community. As a result of the differences in their physical appearance, children with albinism are often rejected by their communities. This places them at great risk of being harmed (Nebre, 2018).

Studies indicate that Sub-Saharan Africa has the greatest dominance of individuals with albinism who are being discriminated against (Franklin et al., 2018; Nakkazi, 2019; Nebre, 2018). According to Kiluwa et al. (2022), children with albinism are socially vulnerable and as a result, they often experience psycho-trauma, which has an effect on their health and learning. Most of the problems that children with albinism encounter therefore do not stem from their physical appearance resulting from the condition of albinism, but rather from how others in the environments they find themselves in, respond to their disparities. (Gaigher et al., 2002). Furthermore, due to an absence of awareness and knowledge of albinism in Sub-Saharan African societies, the stigmatisation experienced by children with albinism, as well as inadequate healthcare, these children are deprived of a quality of life (Kromberg et al., 2020).

Children with albinism are profoundly entrenched in various myths pertaining to albinism (Daklo & Obadire, 2024). In selected parts of Sub-Saharan Africa, individuals of African descent are under the impression that the body parts of children with albinism have mystical abilities (Lund & Lynch, 2012). A mother of a baby with albinism in South Africa's Limpopo province recounted her experience of being ashamed of her child due to his condition and was compelled to keep him hidden from the public. However, after receiving counselling from a nurse with knowledge of the genetic factors that cause albinism, the mother was capable of showing her child to the community and providing explanations for his condition (Baker et al., 2010).

According to Baker et al. (2010), in many rural areas of Zimbabwe and South Africa's Limpopo province, numerous infants with albinism are disowned, abandoned and left to die. In Uganda, for example, the shock and fear of some nurses and healthcare personnel at the sight of a child born with albinism increase the anxiety experienced by parents of children born with albinism (Reimer-Kirkham et al., 2024).

In other parts of sub-Saharan Africa such as Tanzania, the lives of children with albinism are also endangered since they are pursued for their bodies, which are believed to be a sign of good fortune. The violations practised in Sub-Saharan Africa remain a critical human rights concern (Lund & Lynch, 2012). This affects three sustainable development goals (SDGs), namely good health and well-being (Goal 3), quality education (Goal 4) and reduced inequalities (Goal 10) (Gupta & Vegelin, 2016; Yumnam et al., 2024).

In many regions in South Africa, individuals with albinism face human rights atrocities (Hargovan & Rovashni, 2023). Mswela (2022) states that due to a lack of understanding and knowledge regarding the well-being of children with albinism, interventions to enhance, support, encourage, and safeguard them remain elusive. The under-researched area of the influence of broader social structures regarding individuals with albinism remains, resulting in health and social biases, and gaps in policies to safeguard the lives of individuals with albinism (Reimer-Kirkham et al., 2024). Owing to a lack of awareness, gaps in policy, stigmatisation, and discrimination against children with albinism, their parents are often uninformed about their condition and therefore hold various inaccurate perspectives on the social justice needs of these children.

1.2 PURPOSE STATEMENT

The purpose of this study of limited scope was to explore and describe parental perspectives on the social justice needs of children with albinism. I therefore aimed to explore the social justice challenges that children with albinism experience and how this affects their parents. In addition, I described the role of parents in relation to the social justice needs of children with albinism. As part of this study, I also provided recommendations regarding the strategies parents may utilise to support the social justice needs of children with albinism.

1.3 RESEARCH QUESTIONS

The following primary research question: How do parents perceive the social justice needs of children with albinism? guided this study. In an attempt to respond to the primary research question, I was guided by the subsequent secondary research questions:

- Which social justice challenges are experienced by children with albinism in South Africa (as perceived by their parents)?
- What is the role of parents in relation to the social justice needs of children with albinism?
- Which strategies can be utilised to support the social justice needs of children with albinism (according to their parents)?

1.4 CLARIFICATION OF KEY CONCEPTS

Throughout this section, I refine the key concepts that guided this study of limited scope.

1.4.1 Parent

A parent is referred to as any natural parent or guardian of the child (Machingambi, 2023). A person can be considered a parent if they are lawfully entitled to guardianship of a child (South African Council of Educators, 2002). According to Virasiri et al. (2011), a parent is an individual who maintains the role and responsibility of providing for a child's physical and psychosocial needs. A parent is furthermore an individual who positively supports every form of development in a child's life (Virasiri et al., 2011). In the context of this study, a parent refers to the mother, father, or guardian of a child with albinism, who holds various perspectives on the social justice needs of children with albinism due to the difficulties that their children experience in societies as a result of their condition.

1.4.2 Perceptions

Perception involves the way one sees the world (McDonald, 2012). Perception includes the collection and understanding of information from our environment and the derivation of meaning from that information. It is a cognitive process that creates a view of the world that is often different to reality. This means that no individual will have the same lived experiences

(Amodu, 2007). In this study, perceptions include opinions, beliefs and ideas of parents that are derived from children's experiences with albinism.

1.4.3 Social justice needs

Social justice implies that every person ought to have equal economic, civil, and social rights and opportunities (Jun, 2024). The importance is rarely on equalisation but rather on an equitable, social, and cultural system that is equally designed and caters for the needs of all children regardless of their ethnicity, linguistic, gender, or economic background, and political association (Mafumo, 2011). In this study, social justice needs refer to equal education opportunities, safety and security, healthcare, and freedom from stigmatisation and discrimination of children with albinism. Some hold the belief that children with albinism must be accommodated in mainstream schools, instead of being referred to special needs schools (Franklin et al., 2018).

1.4.4 Children with albinism

The word 'albinism' originates from the Latin term 'albus', suggesting white (Phatoli et al., 2015). Albinism is a genetic disorder triggered by a paucity of melanin formation (Franklin et al., 2018). The condition is first noticed when a child is born and persists during the remainder of the child's lifetime. Children are more susceptible to being born with albinism if both their parents carry the specific DNA and have albinism (Lynch et al., 2014). In the context of this study, children with albinism are individuals under the age of 18 who, as a result of their condition (albinism), suffer from extreme issues of stigmatisation and discrimination, and are exposed to myths and stereotypes based on the colour of their skin and hair.

1.5 WORKING ASSUMPTIONS

The current study was conducted against the background of the following working assumptions:

- Parents are able to strengthen and support the social justice needs of children with albinism.
- Parents are potential resources that can promote the importance of social justice for children with albinism.
- Parents are able to identify the social justice needs of children with albinism.
- Parents are able to make recommendations regarding ways in which the social justice needs of children with albinism can be supported.

1.6 THEORETICAL FRAMEWORK

In South Africa, individuals with albinism are viewed as disabled due to the visual impairments associated with albinism (Mswela, 2018). Children with albinism are susceptible to numerous challenges due to their condition (Lund & Lynch, 2012). As a result, I adopted the social model of disability (Oliver, 2013) as my theoretical framework for the current study. The social model of disability (Oliver, 2013) perceives disability as a socially constructed phenomenon (Ferreira & Sefotho, 2020). This means that disability is recognised as a challenge deriving from society (Owens, 2014). According to the social model of disability (Oliver, 2013) individuals can be seen as having a disability if their social, political, cultural, and economic environments do not cater for their needs based on their impairment (Anastasiou & Kauffman, 2013).

The social model of disability (Oliver, 2013) indicates that the environments in which individuals find themselves have not adapted to or possess the appropriate knowledge to assist individuals with disabilities (Ferreira & Sefotho, 2020). A lack of knowledge regarding albinism, and poor adaptation to environments, as well as experiences faced by children with albinism, create barriers to their learning and growth which result in the social justice needs of children with albinism being impeded. The social model of disability (Oliver, 2013) guided the current study as it promotes the inclusiveness of individuals with disabilities and the elimination of barriers created by society. This includes changing the attitudes of the public towards people with disabilities, and environmental and structural impediments (Ferreira & Sefotho, 2020).

1.7 PARADIGMATIC PERSPECTIVES

In the following sections, I provide an overview of the epistemological and methodological paradigms that guided this study. A detailed discussion is provided in Chapter 3.

1.7.1 Epistemological paradigm

I utilised interpretivism (Creswell & Poth, 2018) for this study. Interpretivism focuses on the relationship between the researcher and the participants (Kivunja & Kuyini, 2017). In addition, interpretivism provides insight into the individual rather than the world around them (Ngula, 2023). Interpretivist researchers believe that reality is socially created, which means that we can only understand an individual’s reality through their experiences of their environment (Ngula, 2023).

Interpretivism additionally considers differences in cultures and circumstances prominent to the advancement of several social realities (Alharahsheh & Pius, 2020). The interpretive paradigm was appropriate for this study as it assisted me in developing a pattern of meaning (Creswell & Poth, 2018). Interpretivism also provided me with a clear understanding of the experiences and perceptions of parents regarding the social justice needs of their children with albinism (Creswell & Poth, 2018).

1.7.2 Methodological paradigm

The current study of limited scope was conducted by utilising a qualitative research approach (Flick, 2014). According to Sutton and Austin (2015), a qualitative researcher attempts to interpret individuals by studying their experiences of the world. The focus of qualitative research is on inner perspectives rather than outer perspectives as the researcher tends to focus on participants' thoughts and feelings through their experiences (Sutton & Austin, 2015). In addition, a qualitative research approach involves descriptions that the researcher uses to find meaning and to obtain insight into the participants through words and illustrations (Atieno, 2009).

According to Flick (2014), qualitative research approaches study local knowledge and practices; this is relevant to the current study as it considers the local knowledge of albinism in South Africa. In addition, a qualitative approach assisted me in finding meaning and developing notions and insights into my study; this aligned with the objectives of the study as it assisted me in understanding the social justice challenges encountered by children with albinism (Creswell & Poth, 2018).

1.8 OVERVIEW OF RESEARCH METHODOLOGY

In the following sections I introduce the research design, the selection of the research site and the participants, as well as the data generation and documentation and the data analysis. A detailed discussion is provided in Chapter 3.

1.8.1 Research design

I implemented an intrinsic case study design in the present study (Stake, 2013). I selected a case study research design while applying Participatory Reflection and Action (PRA) principles (Lawson et al., 2015). PRA involves equal collaboration between the researcher and the participants to define the research problem (Ebersöhn et al., 2012). Creswell and Poth (2018) states that case study designs provide a thorough analysis of a case confined to the time and place of single or multiple cases over a period of time.

Stake (2013) asserts that when selecting cases for a case study, the researcher should approach the case as an opportunity to learn. Applying PRA (Lawson et al., 2015) principles assisted me in interacting with the participants with the aim of learning from their experiences, which helped me understand the situations they faced in their surroundings. In the current research study, I used an intrinsic case study design, which focused exclusively on an individual case to gain a comprehensive understanding of the case (De Vos et al., 2011).

An intrinsic case study design limits the focus on the broader social issue and relatively focuses on the case being studied (De Vos et al., 2011). An intrinsic case study design, therefore, assisted me in focusing on parents' perceptions of the social justice needs of children with albinism and the challenges children with albinism face in their surroundings due to their condition. This provided me with an understanding of how to support children with albinism (Kiluwa et al., 2022).

1.8.2 Selection of research site

The Centre for Visual Impairment Studies (CVIS) at the University of Pretoria has a good working relationship with schools for the blind and children with visual impairment in Gauteng. Based on this, convenience sampling was used (Farrokhi & Mahmoudi-Hamidabad, 2012). I relied on purposive sampling (Rai & Thapa, 2015) to select my case (primary school) where I focused on a group consisting of eight participants, namely parents of children with albinism from the selected school.

1.8.3 Selection of participants

To align my study with interpretivism and a qualitative research approach, I utilised convenience and purposive sampling to select the participants (Etikan, 2016). I selected eight parents of children with albinism as participants in a school for special needs children with visual impairments. My focus was on children with albinism in the intermediate phase. Purposive sampling consists of a selection of participants based on the participants' qualities. In addition, the participants' inclusion allows development in research concerning the topic studied (Emmel, 2013).

An advantage of purposive sampling is that it includes a broad range of sampling methods that can be applied to qualitative research designs (Rai & Thapa, 2015). Furthermore, purposive sampling diverges from utilising random forms of sampling and ensures that the participants required for specific kinds of cases are included and are part of the final sample in the research study (Campbell et al., 2020) In addition, purposive sampling offers a wide range of non-probability sampling methods for the researcher to utilise and is an inexpensive and less time-consuming method (Rai &Thapa, 2015).

A challenge of purposive sampling is that it can result in researcher bias as the method is based on the researcher's judgement (Andrade, 2021). This further leads to the challenge of convincing the reader why the judgment used to select participants is appropriate and utilising purposive sampling to achieve theoretical generalisation (Rai & Thapa, 2015). I needed to have an awareness of the differences and attitudes, opinions, or manifestations held by the participants regarding the phenomenon of interest. To avoid biases, I focused on personal self-awareness, thus opening and building stronger relationships and preventing prejudices (Ketokivi, 2019). I had to determine my target audience and ensure that participants were given an equal opportunity to ensure that relevant accurate data was collected. I furthermore, had to reassure my participants that their answers would be kept confidential and would only be used for the purpose of the study (Ketokivi, 2019).

1.9 DATA GENERATION AND DOCUMENTATION

To generate data for this study of limited scope, I utilised focus groups, PRA activities, observations, audio-visual recordings, field notes and a reflexive journal (Creswell & Poth, 2018). I incorporated PRA activities when working with the participants as the participants were generating data and information during their sessions with me (Putman & Rock, 2017). In addition, I incorporated activities that encouraged parents to reflect on the experiences of their children with albinism (Corn & Lusk, 2018).

To better understand parent participants' perceptions of the social justice challenges that their children with albinism face, focus groups were conducted to gather parents' opinions (Krueger, 2014). Focus groups assisted me in identifying trends and patterns in the parents' perceptions (Krueger, 2014). I also used audio-visual recordings that were transcribed (Bates, 2013). In terms of visual data, parent participants were encouraged to create posters indicating the various types of social justice challenges experienced by children with albinism (Gray et al., 2022).

Sessions with focus groups was conducted after school hours to ensure the availability of parents. Once data was generated, it was analysed for codes and themes (Braun & Clarke, 2021). Participants were contacted for the member-checking session to ensure that the data generated was accurate (Candela, 2019). Participants were furthermore given an opportunity to change or add to their responses during the member-checking session.

I utilised a reflexive journal in this study of limited scope (Browne, 2013). In qualitative research, a reflexive journal is a research tool (Browne, 2013). Practical decisions made during the data generation process and the researcher's personal feelings were recorded in the reflexive journal (Meyer & Willis, 2018). This allowed me to refer to the data if the need arose to advance my understanding of the data (Browne, 2013). I also utilised a reflexive journal to record all the methodological steps taken to gather data (Browne, 2013). I furthermore, used a reflexive journal to document all my findings during the study (Meyer & Willis, 2018).

To document and reflect on my insights, as well as parents' perceptions of children with albinism, I also utilised field notes (Sutton & Austin, 2015). My reflexive journal assisted me in my meaning-making process and supported me in acquiring information on the unique occurrences I observed (Browne, 2013).

1.10 DATA ANALYSIS

As part of the current study, I began my data analysis process by incorporating Braun and Clarke's (2023) six-phase guide to conducting reflexive thematic analysis. I started out by familiarising myself with the data (step 1); I then generated initial codes (step 2); I subsequently searched the data for themes (step 3); I reviewed the themes I had found (step 4); I then provided definitions for the themes (step 5); and I finally wrote up my findings (step 6) (Braun & Clarke, 2023).

Reflexive thematic analysis is regarded as the researcher's interpretation of the data gathered as examined in the study (Byrne, 2021). Reflexive thematic analysis is appropriate for this study of limited scope because it allowed me to detect uniformities and differences among the parent participants' responses regarding their experiences as parents of children with albinism; this assisted me in accumulating responses to the research questions (Terry & Hayfield, 2020). Reflexive thematic analysis was utilised to identify, and ideally articulate, the reporting of the findings and the theoretical assumptions informing the analysis (Braun & Clarke, 2021).

1.11 ETHICAL CONSIDERATIONS

During my study, I adhered to the University of Pretoria's Code for Ethical Research (University of Pretoria, 2015). This entailed requesting permission from the Department of Basic Education, as well as obtaining permission from the primary school to carry out the proposed study with parents of children with albinism (Maree, 2016a). This included the approval of the principal and members of the school governing body (SGB). I treated participants with respect and considered ethnic and religious differences between the participants and myself (Flick, 2014).

Trust and honesty were established at the start of the research process (Maree, 2016a). Participants were required to complete consent forms in which confidentiality was discussed (Elias & Theron, 2012). The identities of the participants and the schools participating in the study were not divulged (Maree, 2016a). Furthermore, data gathered in the study was stored at the Centre for Visual Impairment Studies (CVIS) at the Faculty of Education (University of Pretoria). The data was kept safe and would only be accessible to the supervisor and members of the research study team (Maree, 2016a).

In addition, I assured the participants that their answers would be kept confidential. However, I was not able to guarantee confidentiality between the participants in the study (Elias & Theron, 2012). Participation was voluntary and no coercion or deception was used (Mouton, 2001). If any of the participants did not want to continue with the study, they were welcome to remove themselves before, during or after the research process (Mouton, 2001). If there was any indication of harm arising during the study, participants were referred to mental health professionals. As I was dealing with participants from different ethnicities to my own, I was required to employ cultural sensitivity (Dixon et al., 2016). Lastly, all research findings were shared with the participants (Elias & Theron, 2012).

1.12 QUALITY CRITERIA

The quality criteria of the study refer to the trustworthiness of the study (Gunawan, 2015). In this study, I adhered to the following criteria: credibility, transferability, confirmability, dependability, and authenticity (Lincoln & Guba, 1985). Credibility is defined as how convincing or believable the findings of the research study are concerning the degree of agreeableness between the researcher and participants (McGinn, 2012). Credibility was established during member-checking and debriefing sessions, my reflexive journal and creating field notes, and audio-visual recordings (McMillan & Schumacher, 2010). Transferability is related to the level at which the results from the study can be employed under similar circumstances (Maree, 2016b). As stated before, my aim was not to generalise findings, however, the results of this study could be transferred to related settings due to the detailed explanations and information generated (Maree & Hansen, 2011).

Confirmability refers to the process where findings from the research study are reflected by the thoughts and ideas of the participants instead of the motivations and biases of the researcher (Nieuwenhuis, 2016). In this study, all findings were documented from the data generated and all methods and decisions made were transparent (Maree & Hansen, 2011). Dependability, on the other hand, signifies how the research findings can be reproduced with participants if they occurred in related settings (Maree, 2016b). In this study, data generated was documented in a detailed logical process in support of dependability. In addition, I also developed an audit trail (Lincoln & Guba, 1985).

Finally, authenticity implies the relevance and value of the findings of the research study to the participants and the community where the study had been carried out (James et al., 2008). I aimed for authenticity by gaining detailed findings from the parent participants regarding their perceptions of the social justice needs of children with albinism. The detailed findings were captured during the focus group by means of audio-visual recordings.

1.13 OUTLINE OF THE CHAPTERS

In Chapter 1, I introduced this study and provided a brief outline by highlighting the background and rationale for undertaking the study. In Chapter 2, I focused on current literature and the theoretical framework utilised in the study. Chapter 3 focused on the selected epistemological and methodological perspectives, the research design, selection procedures, data generation and documentation techniques and data analysis procedures that were used. In Chapter 4, I present the results of the study's findings according to the themes and sub-themes found during the inductive thematic analysis. I also interpreted the results against existing literature in order to demonstrate my findings. Lastly, in Chapter 5, I conclude and reflect on challenges and limitations by summarising the findings of the study. I then reflect on strengths that added potential value to the study and conclude with possible recommendations for future research and practice.

1.14 CONCLUSION

In this chapter, I contextualised my study and explained the rationale for undertaking the study. I furthermore stated my research questions, as well as the purpose and working assumptions that guided me. I then clarified the key concepts and introduced the epistemological and methodological perspectives used in the study. I furthermore discussed the research process in terms of the research design, selection procedures, data generation and documentation, as well as the analysis of the data. I then briefly outlined the theoretical framework that led my study and briefly indicated the ethical considerations and quality criteria I adhered to.

In the final chapter, I discuss the literature relating to my study on parents' perceptions of the social justice needs of children with albinism and explain the theoretical framework of the study.

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CHAPTER 2 - LITERATURE REVIEW AND UNDERPINNING THEORY

2.1 INTRODUCTION

In Chapter 2, I explore existing literature regarding parental perspectives on the social justice needs of children with albinism, the prevalence and causes of albinism within the South African context, the challenges faced by children with albinism, and the impact of albinism on their development. I also explore stereotyping and discrimination faced by children with albinism, as well as barriers to promoting social justice in the school-context for children with albinism. I subsequently focus on national efforts and strategies that have been put into place to address the social justice needs of children with albinism. I conclude the chapter with a discussion of the study's theoretical framework.

2.2 UNDERSTANDING CHILDREN WITH ALBINISM

In the following section, I contextualise the experiences of children with albinism by discussing the definition, characteristics, prevalence and causes of albinism, as well as the challenges faced by children with albinism and the impact on their development in the South African context.

2.2.1 Definition and characteristics associated with albinism

The word albinism results from the Latin word *"albus"* which means white (Ringson, 2018). Albinism is an inherited condition that results from a scarcity in the production of melanin, a substance present in the skin that produces pigment (Franklin et al., 2018). The appearance of individuals with albinism includes white skin, light-blonde hair, light coloured and occasionally reddish eyes (Ngula, 2023). Various types of albinism occur, with the most common and visible form being oculocutaneous albinism (Franklin et al., 2018).

Oculocutaneous albinism (OCA) is classified into seven types, ranging from oculocutaneous albinism type 1 (OCA1) to oculocutaneous albinism type 7 (OCA7) each caused by mutations in different genes (Ray et al., 2017). Another form of albinism is ocular albinism, a condition that affects the eyes of individuals with albinism. This form of albinism is not common and is mainly found in males (Ngula, 2023). The hair and skin colour of children with ocular albinism may appear faintly lighter than the rest of their family members (Ngula, 2023).

The result of an absence or minimal melanin production in individuals with oculocutaneous albinism leads to various physical and physiological conditions (Pooe-Monyemore et al., 2012). A lack of skin pigmentation increases individuals' skin sensitivity resulting in harmful effects from exposure to the sun (Franklin et al., 2018). The effect of harsh sunlight can lead to skin cancers and can aggravate eye conditions resulting in poor vision, nystagmus, photophobia, reduced visual acuity, and deflective errors (Franklin et al., 2018).

In a study of children with albinism in South Africa, approximately 85% were believed to have 30% vision even while having the assistance of optical modification (Bradbury-Jones et al., 2018). Children with oculocutaneous albinism may experience abnormal development of the optic nerve, resulting in poor vision and other eye conditions (Pooe-Monyemore et al., 2012). When individuals with albinism are exposed to ultraviolet radiation their skin becomes prone to damage which increases the risks of cancer (Zungu & Mashige, 2019). It is therefore crucial that individuals with albinism protect their skin from a young age by applying sunscreen and avoiding unnecessary exposure to the sun (Zungu & Mashige, 2019).

2.2.2 Prevalence and causes of albinism

Albinism affects various populations around the world regardless of an individual's gender or ethnicity (Franklin et al., 2018). Children with albinism inherit the condition in an autosomal recessive manner; this means that the child with oculocutaneous albinism inherits two defective genes, one from each parent (Pooe-Monyemore et al., 2012). For albinism to be transmitted from parents to their children, both parents are required to have the gene that causes albinism (Ngula, 2023). However, in most cases, children with albinism are born to parents who carry the gene but do not have the condition of albinism (Ngula, 2023).

Albinism is estimated at 1:17000 to 1:20,000 globally (Ajose et al., 2014; Federico & Krishnamurthy, 2023). One in 70 individuals has an OCA-mutated allele (alternative versions of a gene). OCA1 is most commonly found in American and Chinese populations with a prevalence of 1 in 40 000; OCA2 is most commonly found in African American (1:10 000) and Sub-Saharan African populations (1:3 900) (Federico & Krishnamurthy, 2023). The prevalence of OCA3 is 1:8500 of African individuals mainly in Sub-Saharan Africa. However, this subtype of albinism is also found in Pakistani, German, Indian and Japanese population groups (Federico & Krishnamurthy, 2023). The OCA4 subtype has a prevalence of 1:100 00 accounting for mainly Japanese groups (Federico & Krishnamurthy, 2023; Ray et al., 2017). The remainder of oculocutaneous albinism subtypes, OCA5, OCA6, and OCA7 are considered rare types of oculocutaneous albinism (Federico & Krishnamurthy, 2023).

2.2.3 Individuals with albinism as a vulnerable group in South Africa

In South Africa, every individual has the right to life and the right to human dignity (Franklin et al., 2018; Mswela, 2017). The South African government therefore has a significant influence over the individual who is committing the crime of killing people with albinism (Mswela, 2017). The reality of killing individuals with albinism is that the victims cannot be compensated for something that cannot be restored. It is nonetheless the state's responsibility to safeguard children with albinism from violence (Mswela, 2017; Nkrumah, 2021).

In October 2013, a document known as the Ekurhuleni Declaration on the Rights of Persons with Albinism was compiled by the State (Mswela, 2017). The declaration emanated from the first National Albinism Conference in Ekurhuleni, Gauteng, where the South African government provided a declaration of recommendations for addressing violent crimes against individuals with albinism. These included systems to be established to collect data on the social justice of individuals with albinism and the development of legislation to enforce disciplinary action against those who commit acts of violence against individuals with albinism or harm them in any way. It furthermore encourages the South African Human Rights Commission to launch an investigation into the violation of human rights experienced by individuals with albinism (Mswela, 2017; Nkrumah, 2021). Despite these recommendations, a follow-up regarding the progress of the declaration revealed that the State has not been abiding by these commitments (Mswela, 2017).

While compared to other countries in Sub-Saharan Africa, South Africa does not have a high rate of albinism killings, however, the killing of individuals with albinism still takes place in some parts of the country (Nkosi et al., 2023). Knives and machetes are often used as tools to sever the body parts of victims with albinism resulting in brutal murders (Mswela, 2017). This causes individuals with albinism to be reluctant when walking alone, travelling or being alone in public (Hargovan & Rovashni, 2023). As a result, individuals with albinism are viewed as a vulnerable group; like all other individuals in South Africa, they have equal rights to safety and security (Nkrumah, 2021). The right to human dignity, as well as the right to life and equality, cannot be overlooked when considering individuals with albinism (Franklin et al., 2018; Mswela, 2017).

Individuals with albinism are an extremely vulnerable group in society and are often ridiculed for their appearance. The Bill of Rights (Currie & Waal, 2013), states that every individual holds the right to freedom and security, including not being disadvantaged in terms of freedom subjectively or without reason; not being imprisoned without trial; being entirely free from violence; not to be tortured; or subjected to punishment in a punitive, inhumane, or humiliating manner.

In South Africa, most of the victims of violence against people with albinism are children (Hargovan & Rovashni, 2023). It has been reported that in some areas in South Africa, violence against children with albinism has resulted in their right to education being violated because they are afraid to go to school due to the fear of being attacked (Franklin et al., 2018; Mswela, 2017). Since many individuals with albinism and their families live in fear of violent attacks, the government should intervene to prevent these crimes (Maluleke et al., 2023). According to Nkosi et al. (2023), South Africa does not have any consolidated legislation in terms of disability even though policies and legislation regarding disability do exist.

2.2.4 Challenges faced by children with albinism

Children with albinism experience slight delays in their developmental milestones due to the visual challenges associated with their condition (Kromberg & Kerr, 2022). In addition to the health challenges that they face, children with albinism also experience psychological and social challenges. They are often shunned, ridiculed and discriminated against due to their condition (Mswela, 2017; Kromberg & Kerr, 2022). As a result, children with albinism tend to avoid social situations to protect themselves from being rejected (Mswela, 2017). Stigmatisation leads individuals with albinism to internalise the harmful reactions from members of communities, which leads to children with albinism experiencing feelings of shame and self-blame (Mswela, 2017).

As indicated, the visible differences associated with albinism have an impact on children’s social interactions. They tend to develop emotional problems such as low self-esteem, poor coping mechanisms and poor social skills (Kromberg & Kerr, 2022). In terms of the psychosocial issues that children with albinism experience as a result of the stigmatisation and discrimination they face, they find it hard to be in new social situations, which in turn leads to social segregation (Kromberg & Kerr, 2022). Loneliness and isolation are probable causes that promote feelings of unhappiness and depression in children with albinism (Sefotho & Ferreira, 2020).

Children with visual impairment furthermore often experience feelings of negativity, frustration, sadness and unfairness in the school environment (Sefotho & Ferreira, 2020). This may be in relation to the school setting and atmosphere as well as interactions with teachers, peers and other individuals who do not accept and respect learners with albinism for as human beings (Sefotho & Ferreira, 2020).

A lack of knowledge about the fact that albinism affects skin pigmentation, may lead to children with albinism developing skin cancer (Nakkazi, 2019). As a result, some individuals with albinism die prematurely. According to Mswela (2022), parents of children with albinism are often reluctant to seek medical assistance due to the fear of being rejected. In terms of self-confidence and self-determination, research indicates that children with albinism, who also have visual impairment, often have low self-esteem; they find it tough to face the partial loss of their sight and tend to feel different from other people (Sefotho & Ferreira, 2020). However, some children with visual impairments who suffer from low self-esteem, have encouragement to persevere, are admired for prior accomplishments and successes, and have the support of their friends to help them cope with their condition. Other children with albinism on the other hand may possibly need specialised psychological counselling to assist them with the emotions they experience as a result of their condition (Sefotho & Ferreira, 2020).

The social rejection of individuals with albinism due to superstitious beliefs results in inner struggles for children with albinism as they tend to experience alienation from society, which leads to inferiority complexes (Mtonga et al., 2021). As a result of superstitious beliefs, individuals with albinism have been kidnapped, killed and dismembered in various African countries during the past ten years. Contemporary records reveal that between 2006 and 2017, nearly 190 homicides and 515 assaults against individuals with albinism occurred in 27 African countries (Kromberg & Kerr, 2022).

According to Tambala-Kaliati et al. (2021), studies indicate that socialisation is a challenge for children with albinism from a young age because of the differences in their skin colour and nystagmus. As such, children with albinism often experience feelings of frustration, sadness, being unfairly treated, and disappointment (Sefotho & Ferreira, 2020). These feelings originate in the school environment due to rejection and a lack of respect from their peers and others who see them as different (Sefotho & Ferreira, 2020). When other children notice the differences between themselves and children with albinism, they tend to socially isolate from these learners, which can lead to loneliness (Sefotho & Ferreira, 2020).

2.3 SOCIAL JUSTICE RELATED TO CHILDREN WITH ALBINISM

To contextualise parental perspectives on the social justice needs of children with albinism, I first define social justice. I subsequently discuss the importance of social justice for children with albinism and the barriers to promoting social justice in the school context.

2.3.1 Definition of social justice

Social justice involves identifying and redressing structural disadvantage, discrimination, and inequality (Hargovan, 2023). The aim of social justice is to promote a society that values equality, diversity and respect irrespective of an individual's background, disability, gender, age, ethnicity, sexual orientation or religion (Bhugra, 2016). Social justice ensures fair allocation of resources and support for human rights (Bhugra, 2016).

Societal and environmental barriers prevent children with albinism from participating equally in society due to the discriminatory practices they face (Hargovan, 2023). This is built on the fact that children with albinism appear physically different from other individuals owing to the colour of their hair, skin and eyes as a result of their condition; based on this, they are often viewed and treated differently (Hargovan, 2023).

2.3.2 Importance of social justice for children with albinism

Because of their condition, children with albinism face numerous challenges in terms of wellbeing, safety and security (Reimer-Kirkham et al., 2024). Challenges range from their physical problems, including visual impairment and the risk of skin cancer, to psychosocial problems as a result of stigma and discrimination (Reimer-Kirkham et al., 2024). Furthermore, in some regions in Sub-Saharan Africa, individuals with albinism are mutilated and murdered for their body parts (Cruz-Inigo et al., 2011).

Children with albinism additionally often face social isolation due their appearance and lack access to health and support services (Mwajabu & Joseph, 2018) as a result of poor socio-economic conditions. Advocacy and policy on albinism and human rights therefore need to be established to protect the well-being and lives of individuals with albinism. This is an especially pressing matter since social justice will certify that individuals with albinism have full and fair admittance to activities, education, health and safety, and are not discriminated against on the grounds of their disability (Mwajabu & Joseph, 2018).

In South Africa, families of children with albinism often have inadequate resources accessible to them, predominantly in rural areas where amenities for education and intervention are constrained (Ferreira & Sefotho, 2020). In terms of social justice, equal resource distribution should be available to all South African citizens. This means that the needs of children with albinism should be catered for in the same way other citizens in the country receive support (Nkosi et al., 2023).

According to the Albinism Society of South Africa, the nationalised health scheme is inadequate in taking into consideration and accounting for the healthcare requirements of children with albinism (Mswela, 2022). Recognising their right to health support as stated in the Constitution of South Africa (1996), individuals with albinism may confront the state's non-fulfilment of providing appropriate healthcare amenities and health accessories to assist them with their condition (Constitution of the Republic of South Africa act 1996, 2021).

2.3.3 Barriers to promoting social justice in the school-context for children with albinism

In addition to the legal, physical and psychosocial problems that children with albinism face, they also experience educational challenges (Mtonga et al., 2023). Children with albinism therefore require a school setting that focuses on and is aware of their condition thus making provision for them in accordance with their condition and needs (Franklin et al., 2018). In South Africa’s rural areas, special schools that cater for children with albinism are limited, resulting in a large number of children with albinism being excluded from educational opportunities (Mswela, 2017).

A study by Lund and Lynch (2012) reveals evidence that the turnout of children with albinism in learning facilities remain low due to these children being bullied by peers, as well as the lack of knowledge among teachers on how to deal with their condition. Furthermore, vicious attacks and killings of people with albinism cause other individuals with albinism to live in fear (Mtonga et al., 2023). As a result, some children with albinism stay away from school due to fear of being harmed (Mswela, 2017). In some areas children with albinism do not attend school owing to the belief that they are not worth educating and that they are considered incapable of contributing to society in the same way that other members do (Franklin et al., 2018).

According to Kromberg et al. (2020), many children with albinism attend education institutions for the visually impaired. However, it would be possible for them to attend mainstream schools if the necessary accommodations were made and inclusive education was established (Franklin et al., 2018). Kromberg et al. (2020) indicate that if teachers had knowledge of how to support children with albinism in mainstream schools, these learners would not need to attend special needs schools (Kromberg et al., 2020). Among the challenges that children with albinism face at mainstream schools, is that the font size in textbooks is too small for them to read with ease due to nystagmus and low vision associated with the condition of albinism. This further exacerbates their difficulty to adapt in mainstream schools. (Tambala-Kaliati et al., 2021).

The effect of their academic challenges is that children with albinism have little motivation to attend higher education institutions and follow their future dreams and aspirations, as well as partial subject choices with implied limitations of vocational opportunities (Sefotho & Ferreira, 2020). Lourens and Swartz (2016) assert that children with visual impairment may experience difficulty with transition into the adult world due to the various constraints they face. Moreover, besides being marginalised and rejected from partaking in all-encompassing environments, the effect of these children's condition may result in physical limitations that aggravate their feelings of being unalike; as a result, this can complicate the likelihoods of optimally attaining any goals in their lives after they have completed high school (Sefotho & Ferreira, 2020).

2.4 FACTORS INFLUENCING PARENTAL PERSPECTIVES ON THE SOCIAL JUSTICE NEEDS OF CHILDREN WITH ALBINISM

To contextualise the factors influencing parental perspectives, parents' socio-economic status needs to be taken into account. In addition, parents' access to information and support networks regarding the condition of albinism must also be explored.

2.4.1 Socio-economic status of parents

Parental involvement in the family, community, and school setting is essential in the treatment of children with albinism (Mukuna & Machingambi, 2023). Parents of children with albinism can assist teachers in supporting their children with learning challenges, including creating Individualised Education Plans (IEPs) and decision-making regarding their children's learning challenges (Mukuna & Machingambi, 2023). However, as a result of many parents' socio-economic status, this is not always the possible. Due to work constraints and responsibilities, parents are often too busy to be involved in the treatment of their children with albinism (Salami & Okeke, 2018). Some parents have to work away from home and only see their children at long intervals. Additionally, socio-economic status plays a role where parents of children with albinism in low-income families do not have the necessary funds to purchase sunscreen for their child's skin condition or to access healthcare services for their child with albinism-related healthcare issues (Likumbo et al., 2021; Mukuna & Machingambi, 2023).

2.4.2 Parent views on education access and quality for children with albinism

Many parents of children with albinism believe that the government should provide free education to children with disabilities as they are concerned that free access to education is currently only available to those who are able (Makwela & Smit, 2022). This forces parents of children with albinism to enrol their children in special needs schools where they incur additional costs (Franklin et al., 2018). Parents believe that policies implemented to protect their children with disabilities are often overlooked. In order for children with albinism to be protected in society, these policies must receive attention and be adjusted with an emphasis on addressing prejudices (Makwela & Smit, 2022).

Parents of children with albinism have indicated that they preferred sending their children to resource centres instead of mainstream schools since in resource centres children with disabilities, such as albinism, are not stigmatised and teachers have a better understanding of their condition (Tumwesigye et al., 2009). In resource centres, some children are not favoured by teachers over others and children with albinism receive love and care. Due to the increased number of children with albinism at such centres there is a better understanding of their condition (Lynch et al., 2014). Parents further expressed that teachers at resource centres play a fundamental role in caring for their children by assisting them with their schoolwork, as well with their social relations, for example helping them form friendships and (Lynch et al., 2014).

Parents of children with albinism are reluctant to send their children to mainstream schools as they fear for the safety and happiness of their children and they believe that their children will not receive the necessary protection and care from their teachers (Franklin et al., 2018; Lynch et al., 2014). This is based on the experiences of other parents of children with albinism who referred their children to mainstream schools and found that their children did not receive the equal care and security they required from the teachers (Machingambi, 2023).

Reimer-Kirkham et al. (2024) indicate that most mothers of children with albinism have limited knowledge regarding their child’s condition. In addition, when children with albinism are born, nurses who are not aware of or understand the condition may be reluctant to touch and hold an infant due to the fear of infection (Kromberg & Kerr, 2022). Some mothers expressed that they were hoping to receive health education regarding their child’s condition when they gave birth to a child with albinism. However, due to an absence of minimal available information, they had to search on the internet for information about the cause of albinism and how to care for their child with albinism (Reimer-Kirkham et al., 2024).

2.4.3 Access to information and support networks of parents

According to Masanja et al. (2020), individuals with little or no formal education have a lower awareness of albinism, whereas those who received a formal level of education have a greater awareness of albinism. Attitudes regarding albinism are associated with elevated levels of illiteracy (Likumbo et al., 2021; Masanja et al., 2020). A lack of knowledge among parents about albinism, affect the way in which children with albinism are taken care of. Parents who have no knowledge of albinism, do not know how to take care of their children with albinism (Tambala-Kaliati et al., 2021). For example, they may not know that due to the sensitivity of their child's skin to the sun, the child is at a higher risk of developing skin cancer (Tambala-Kaliati et al., 2021).

According to Kromberg and Kerr (2022), it is important for parents of a child with albinism to understand the causes of the child's condition, as well as how to help them cope with it. Parents should therefore be referred for genetic counselling after the birth of their child. Genetic counselling should include information about how the condition is inherited, risk factors, prognosis, physical and cultural aspects and ways of addressing health and educational challenges (Kromberg & Kerr, 2022). To ensure greater acceptance of the child within their family and society, a biomedical explanation can enhance people's understanding by accepting a baby with albinism as a human being who merely has a genetic difference (Taylor et al., 2021).

It has been suggested that families of individuals with albinism should be the ones delivering information about the condition in order to provide first-hand knowledge regarding their experiences (Cruz-Inigo et al., 2011). Ongoing public awareness is required to minimise stigmatisation and integration of individuals with albinism in communities (Tambala-Kaliati et al., 2021). It is therefore important for parents of children with albinism to form relationships with family, friends and individuals in their community in order to widen the acceptance of the condition of albinism (Baker et al., 2010).

2.4.4 Cultural beliefs and attitudes towards children with albinism

In many African societies, the etiological beliefs regarding albinism are induced by cultural beliefs and superstition (Ines & Isaack, 2020). The stigmatisation faced by individuals with albinism takes place when an individual represents unwanted features that are not usually found in the characteristics of the group to whom they belong (Brocco, 2016). This leads to the individual being viewed as a reduced person as opposed to what is considered a normal person (Mswela, 2017). This furthermore results in the violation of human rights that affect the well-being of individuals with albinism, thus leading to them being discriminated against (Ringson, 2018).

The fact that individuals with albinism are often hunted for their body parts, results in them further suffering emotionally and physically (Phatoli et al., 2015). The crimes committed against children with albinism include infanticide, kidnapping, amputations, and decapitations (Cruz-Inigo et al., 2011; Mswela, 2022; Nkrumah, 2021). These crimes are performed by using the body parts of children with albinism in witchcraft as it is believed in some African communities that the body parts have magical powers and carry good luck, fortune, and health (Cruz-Inigo et al., 2011). In certain parts of Africa, such as South Africa, incidents of sexual assault occur due to the belief that raping a person with albinism may cure HIV and AIDS (Aborisade, 2022).

Traditional beliefs regarding albinism and the fear of being ridiculed by their community, compel parents to keep their children at home (Tambala-Kaliati et al., 2021). As a result of several misguided beliefs and perceptions regarding albinism, individuals with albinism tend to suffer emotionally as well as physically, which has an impact on their mental health (Ines & Isaack, 2020). In some societies, it is alleged that giving birth to a child with albinism is a consequence of dishonest acts of their mothers (Tambala-Kaliati et al., 2021). This superstitious idea intensifies the aforementioned findings that children with albinism are supposed to be eternal and consequently beneficial in traditional practices (Tambala-Kaliati et al., 2021). Mtonga et al. (2021) assert that in various African societies, individuals with albinism are seen as ‘sacrificial lambs’ – an object to be sacrificed for the benefit of others.

Other myths about albinism include that spitting on an individual with albinism prevents the condition in pregnancy, that children with albinism and their mothers are evil and that albinism is contagious. As a result, children with albinism often feel guilty and fearful forcing them to live in solitude (Cruz-Inigo et al., 2011; Baker et al., 2010). Cruz-Inigo et al. (2011) agree with Mswela (2017) that individuals with albinism have been ostracised and killed in some societies as they are believed to be a curse and a sign of bad luck.

The condition of albinism is associated with both positive and negative attitudes. Negative attitudes include rejecting individuals with albinism and infanticide, while positive attitudes include individuals with albinism being viewed as a symbol of luck (Kromberg & Kerr, 2022).

The myths that surround albinism stem from the fact that individuals with albinism are viewed as neither white nor black, and consequently the position in which this lies within the two worlds of the real world and the spiritual world (Mswela, 2022).

The common myth that albinism is contagious also has an impact on the lives of children with albinism as they are often excluded from socialising with other children due to the concern that they would spread the condition (Baker et al., 2010). This has a detrimental impact on children with albinism at school, where they are excluded from social activities and often face loneliness. Some individuals disallow touching or shaking hands with individuals with albinism, which has an impact on the demonstration of affection towards children with albinism (Baker et al., 2010).

Furthermore, in some communities, when faced with a child with albinism, pregnant women spit on their chests in the idea that the act would inhibit their unborn child from contracting the condition of albinism (Mtonga et al., 2021). The direct aftermath of such unfounded beliefs is the rejection of children with albinism, which leads to psychological difficulties, including detachment from society (Mtonga et al., 2021).

2.5 RECOMMENDATIONS FOR PROMOTING SOCIAL JUSTICE FOR CHILDREN WITH ALBINISM

To promote the social justice needs of children with albinism, I discuss advocacy and awareness campaigns in this section, as well as strategies to promote social justice in the school context.

2.5.1 Advocacy and awareness campaigns to promote social justice for children with albinism

To assist their children, families of children with albinism are frequently required to become advocates for albinism (Franklin et al., 2018). According to Lynch et al. (2014) during a study with parents of children with albinism in a focus group, the parents who were interviewed stated that individuals with an understanding and awareness of albinism should promote the rights of children with albinism in their communities. They should, for example, regularly visit villages and communities to increase knowledge about albinism and dismiss negative beliefs and myths regarding the condition. Through community discussions about albinism, families of children with albinism will be able to develop resilience to face adversities from their communities (Franklin et al., 2018; Lynch et al., 2014).

The state should ensure public awareness about albinism, for example, the fact that apart from the shortage of pigment in the hair, skin and eyes of individuals with albinism, they are no less than any other human beings (Cruz-Inigo et al., 2011). Government should therefore establish security measures in communities to protect individuals with albinism (Ines & Isaack, 2020). In addition, government can create awareness programmes in schools and communities to guard and support the rights of children with albinism (Ajayi & Adelakun, 2020).

Security measures established in Tanzania have proved to be effective as it has resulted in a decrease in the killing of individuals with albinism in that country (Mswela, 2017). The procedures implemented by the Tanzanian government to reduce discrimination against individuals with albinism, proactively contest the stigma, false perceptions and myths surrounding individuals with albinism through awareness campaigns (Brocco, 2016; Mswela, 2017). The South African government can use this as an example to apply the same methods locally.

2.5.2 Strategies for promoting social justice in the school context for children with albinism

Teachers should be conscious of the visual problems that children with albinism may experience in the classroom and should make provision to assist them in learning effectively (Cruz-Inigo et al., 2011). This may include making adjustments in the classroom such as providing access to magnifiers and allowing children with impaired vision to sit in front of the class to see better on the blackboard (Owoeye et al., 2023). Visual aids should be provided, and the classroom should be arranged in such a way that learners with albinism are away from any glare to protect their eyes (Owoeye et al., 2023).

Children with albinism with limited sight should also be able to hold books near their eyes and should be provided with test and examination papers in large, bold lettering. Extra time should be allowed for learners with albinism as they may need additional time to read their test or examination paper due to the visual challenges they experience as a result of their condition (Kromberg & Kerr, 2022).

A common belief among teachers is that children with albinism are associated with subnormal intelligence and that they will therefore perform lower than their peers (Cruz-Inigo et al., 2011). Without appropriate training, teachers cannot fulfil the role of lay counsellors, however, they are often the only persons to whom learners can express their emotional concerns and fears that are experienced at school (Sefotho & Ferreira, 2020). Furthermore, psychotherapy services are not always accessible, this requires teachers to offer support and proceed in the best interest of the learner (Sefotho & Ferreira, 2020).

Teachers can provide support in various ways, for example, through encouragement, and by showing empathy through the implementation of good listening skills to express the necessary compassion (Sefotho & Ferreira, 2020). In addition, it is important that teachers create awareness among other learners in the classroom about albinism thus promoting the personal growth of children with albinism by making them feel welcome and generating feelings of belonging (Franklin et al., 2018).

Teachers are able to further support children with albinism by facilitating contact with other individuals with visual impairment (Owoeye et al., 2023). By helping learners to succeed academically, honouring them for success and encouraging independence, for example, by assisting them with direction, mobility and daily survival skills, can contribute to learners with visual impairments' self-esteem (Sefotho & Ferreira, 2020). A positive sense of worth and self-confidence can as a result promote the autonomy of children with albinism (Ahanonye & Omomia, 2017). It is moreover teachers’ responsibility to educate other learners in the classroom about the condition of albinism to ensure a greater understanding and acceptance of the learner who lives with albinism (Kromberg & Kerr, 2022).

To assist their child with albinism and visual impairment, parents need to ensure that regular assessments are performed, and that their child has access to appropriate visual aids (Kromberg & Kerr, 2022). In terms of their skin, parents must ensure that sunscreen is applied regularly. Regarding psychosocial challenges, parents, as well as their children with albinism, should seek psychological counselling (Hartshorne & Manga, 2018) to help them overcome such challenges.

Social workers and psychologists propose that the parents of children with albinism should receive counselling to help them understand and accept their child’s condition, as well as to assist their child to face stigmatisation and discrimination from their communities (Hartshorne & Manga, 2018; Kromberg & Kerr, 2022). Children with albinism can learn to overcome challenges regarding their condition through supportive therapy. A support group can moreover be beneficial, particularly in groups with other families who have children with albinism (Kromberg & Kerr, 2022).

To understand the parental perspectives regarding the social justice needs of their children with albinism, I continue to discuss the theoretical framework that guided my study. The theoretical framework assisted me to plan and carry out the study, as well as to interpret the results by utilising the existing theory.

2.6 UNDERPINNING THEORY

In South Africa, individuals with albinism are viewed as disabled due to the visual impairment associated with albinism (Mswela, 2018). However, apart from visual impairment, children with albinism are susceptible to several other challenges due to their condition (Lund & Lynch, 2012). I therefore adopted the social model of disability (Oliver, 2013) as my theoretical framework for the study. The social model of disability (Oliver, 2013), views disability as a socially constructed phenomenon (Ferreira & Sesotho, 2020). This means that disability is perceived as a challenge deriving from society (Owens, 2014).

The social model of disability (Oliver, 2013) states that individuals can be seen as having a disability if their social, political, cultural, and economic environments do not cater for their needs based on their impairment (Anastasiou & Kauffman, 2013). In addition, according to the social model of disability (Oliver, 2013) the environments in which individuals find themselves have not adapted to or have the relevant knowledge to support individuals with disabilities (Ferreira & Sesotho, 2020). A lack of knowledge regarding albinism, as well as poor adjustment to the environments and experiences faced by children with albinism, create barriers to their learning and development, which results in the social justice needs of children with albinism being impeded. The social model of disability (Oliver, 2013), which promotes the inclusiveness of individuals with disabilities and eliminating barriers created by society, guided the study. The social model includes changing the attitudes of the public towards people with disabilities, as well as environmental and structural impediments (Ferreira & Sesotho, 2020).

In addition, the social model of disability (Oliver, 2013) focuses on the differences between people with disabilities who are oppressed, and individuals who are non-disabled that trigger and promote the oppression of people with disabilities. According to Shakespeare (2021), the strong point of the social model of disability (Oliver, 2013) is that it has the potential to unify disabled individuals and recognise barriers to injustice. The social model of disability (Oliver, 2013) furthermore underlines the importance of adaptability, compassion, absence of stigma and accommodating surroundings (Shakespeare, 2021).

These aspects of the social model of disability (Oliver, 2013) are essential in assisting children with albinism who are subjected to discrimination, stigma, myths, and stereotyping, and who are placed in special needs schools because of their disability (Kiluwa et al., 2022).

The social model of disability (Oliver, 2013) also aims to protect individual rights, which is critical when addressing social justice challenges faced by children with albinism when several of their rights are infringed upon (Beckett & Lawson, 2021).

2.7 CONCLUSION

In this chapter, I presented relevant literature pertaining to parents' perceptions of the social justice needs of children with albinism, including the current status of albinism in South Africa, as well as the challenges faced by children with albinism that hamper their health and wellbeing. I discussed the rights of individuals with albinism that are affected and the reasons for this. I subsequently focused on possible strategies to assist families and children with albinism and concluded the chapter with a description of the theoretical framework that guided my study.

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CHAPTER 3 - RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

In this chapter, I define, discuss, and justify the paradigmatic perspectives I adopted. I then discuss the research methodology, including the research design and the selection of cases and participants, as well as the data generation, documentation and analysis strategies I utilised. I conclude the chapter with the ethical considerations and quality criteria adhered to during this study of limited scope.

3.2 PARADIGMATIC PERSPECTIVES

In this section, I discuss the principles of an interpretivist epistemological perspective and key characteristics of qualitative research.

3.2.1 Epistemological paradigm

I utilised interpretivism as an epistemological paradigm (Nieuwenhuis, 2015) for this study of limited scope. Interpretivism is founded on the core principle that reality is socially constructed; this allows the researcher to gain an understanding of the deeper implications uncovered in the data of research participants (Maree 2016a; Nieuwenhuis, 2015). Interpretivist researchers aim to interpret and thoroughly understand the relationship between individuals and their environment, as well as the role they play in society (Thanh & Thành, 2015).

Interpretivist research furthermore seeks to understand the subjective meanings and experiences of individuals (Maree, 2016a). Interpretivism also focuses on providing a detailed perspective of a particular context, highlighting how people make meaning out of their experiences (Maree, 2016a).

Interpretivist researchers hold the assumption that researchers can only understand human life from within; therefore, through interactions, individuals can construct their social world through shared meanings (Creswell, 2014; Maree, 2016a; Wahyuni, 2012). By uncovering how meanings are constructed, interpretivist researchers can gain insight into the meaning conveyed as a result of improving their understanding (Maree, 2016a).

According to Creswell (2014), a strong point of the interpretivism paradigm is that researchers can acquire an in-depth understanding of the experience in the context of the individual without generalising or understanding the population as a whole. Furthermore, the interpretive paradigm permits the researcher to view the experience as a whole instead of viewing it in parts (Alharahsheh & Pius, 2020). In this study, it was essential that I considered the relevant situations that affect the psychosocial needs of children with albinism; I therefore viewed their encounters as a whole for an improved understanding. Through formal discussions and interviews, researchers can explore the depth of an individual's experience (Chowdhury, 2014). The advantage of these individuals' experiences is that it can lead to valuable findings and insights (Alharahsheh & Pius, 2020).

The interpretivism paradigm furthermore allows researchers to conduct research in natural settings; as a result, the research can be transferable (Pham, 2018). A further benefit of this paradigm is that it allows interpretivist researchers to deeply understand the viewpoints of their participants within their socio-cultural contexts (Pervin & Mokhtar, 2022).

Interpretivism is criticised for the unstable grounds of judgment leading to the risk of subjectivism (Maree, 2016a; Pham, 2018). The results of interpretivism cannot be generalised beyond the specific context studied as insights gained may not be applicable to broader populations; as a result, the paradigm faces critique in abandoning scientific procedures for verification (Maree, 2016a). Since the interpretivist paradigm is subjective rather than objective, the results may be biased due to the researcher's personal interpretation (Pervin & Mokhtar, 2022).

As a researcher, it was not my purpose to generalise, but rather to understand one case in-depth. The purpose of my study was to understand the experiences faced by a specific group of individuals, namely parents' perspectives on the social justice needs of children with albinism. As part of this study, I had to understand the needs of children with albinism from a specific perspective. Further issues raised against interpretivism, include the small sample sizes of the studies that do not always maintain a concrete hypothesis. However, over time, interpretivist researchers have applied high-quality research practices that counter these arguments (Pervin & Mokhtar, 2022).

The interpretivist paradigm applies to this study as it facilitates the identification of in-depth life experiences, namely parental perspectives on the social justice needs of children with albinism. By analysing the data, researchers can discover, clarify, and express the participants' unique perspectives, in an attempt to place themselves within the participants' viewpoint to uncover the intended meaning (Pervin & Mokhtar, 2022).

3.2.2 Qualitative research approach

I furthermore utilised qualitative research methods for this study of limited scope, as qualitative research methods have the potential to explain processes and patterns of human behaviour that may be challenging to measure (Tenny et al., 2024). A qualitative approach provides participants with the opportunity to explain how, why, or what they are thinking, feeling, and experiencing at a particular time (Tenny et al., 2024).

Qualitative research encompasses notions, concepts, propositions and theories from details (Ritchie et al., 2013). In order to understand parents' concerns and their perspectives on the social justice needs of children with albinism, a qualitative approach was required to find meanings and develop notions and perceptions to assist children with albinism to function effectively in the various contexts in which they find themselves.

A strong point of qualitative research is that through data being generated during discussions, observations and interviews, participants can immediately respond and adapt (Merriam & Grenier, 2019). In addition, the researcher can develop an understanding of verbal and non-verbal communication, process data instantly, review the findings, verify participants’ accuracy in the data they have provided, and explore uncommon or unforeseen responses (Merriam & Grenier, 2019). Because researchers can simultaneously analyse data while it is being generated, they will furthermore have a better understanding of the data (Merriam & Grenier, 2019). This additionally allows researchers to respond to and adapt the data in the moment, allowing for accuracy (Swaminathan & Mulvihill, 2022).

A challenge which occurs in qualitative research is when participants are not able to communicate their feelings and emotions, exchanges and behaviours and therefore face difficulty in responding to discussions and interviews (Atieno, 2009). As a researcher, I was required to ensure that participants were comfortable, and that trust was established so that they could respond to the questions put to them. It was essential to be patient and to provide participants with the relevant time to answer the questions. In addition, it was crucial that I asked questions in a professional manner without offending the participant.

A further challenge related to qualitative research is that biases often occur resulting from factors such as sample sizes or the range of research participants, or when the researcher tries to influence the results (Anderson, 2010). To address this challenge, I had to be aware of my shortcomings in order to eliminate biases. I needed to verify my data sources and ask open-ended questions that allowed for multiple explanations (Chenail, 2014).

3.3 RESEARCH METHODOLOGY

In this section, I provide an in-depth discussion of the research design, the selection of the research site and the selection of the research participants.

3.3.1 Research Design

Case studies differ in comparison to other research methods in the sense that a case study provides an intensive analysis and description of a procedure bounded by space and time (Hancock et al., 2021). I selected an intrinsic case study research design to explore and describe parental perspectives on the social justice needs of children with albinism (Hancock et al., 2021). An intrinsic case study research design is utilised by researchers who want additional information about a particular individual, group or organisation without generalising the findings to other populations and contexts (Hancock et al., 2021). A case was therefore selected to reveal the intricacies of the phenomenon being studied (Stake, 2005). By utilising a case study design, I was capable in delivering a comprehensive and rich account of the personal experiences of the participating parents of children with albinism (Stake, 2005).

A strong point when utilising a case study design is that it allows the researcher to examine and make meaning of the data collected through an in-depth analysis (Ferreira & Sesotho, 2020). An additional advantage of the design is that due to the study taking place in a real-life context (Yin, 2014), the researcher attempts to gain a holistic understanding of the participant’s experiences (Creswell, 2016). Case study designs are furthermore designed to match the case and the research questions, thus allowing flexibility that is seldom offered in other qualitative approaches (Hyett et al., 2014). The case is an object to be studied for a classified purpose that is specific (Hyett et al., 2014).

A limitation of the case study design is that it prohibits the generalisation of findings (Hyett et al., 2014). A challenge occurs when studies are published without sufficient details of the research design; this often confuses the reader and leads to the absence of quality and credibility (Hyett et al., 2014). If the study does not possess adequate descriptions, it can appear to be dishonest and inaccurate (Hyett et al., 2014). To address these challenges, I incorporated appropriate methods and analysis techniques in my study, as well as provided detailed explanations (Crowe et al., 2011). I made use of a reflexive journal to collect information about my experiences and study of participants by noting every detail of the study to provide an in-depth analysis. To achieve transparency, I described all steps involved in the research process in detail. This included the case selection and data gathering methods (Crowe et al., 2011), thus ensuring trustworthiness among the reader and researcher (Crowe et al., 2011).

3.3.2 Selection of research site and participants

Purposive sampling involves studying a population of a specific interest (Andrade, 2020). As a result, purposive sampling leads to an in-depth study with information rich cases which can assist in the answering of research questions and issues of importance considered by the researcher (Palinkas et al., 2013). Purposive sampling, also recognised as judgment sampling, consists of a selection of participants based on the qualities that the participants hold (Etikan, 2016). The researcher's primary objective is to determine the aim of the study and to attempt to find participants who can and are willing to answer the research questions of the study by knowledge or experience (Etikan, 2016). In terms of qualitative research, purposive sampling allows us to identify and select situations that are rich in information to appropriately utilise available resources (Etikan, 2016).

Convenience sampling is a non-probability sampling technique and is commonly adopted as a sampling method in psychology. Convenience sampling collects data in a way that is convenient to the researcher. This means that the organisations' researchers have a relationship with the members at a research site (Scholtz, 2021). In this study, the research site was selected based on convenient sampling and the participants based on purposive sampling. As mentioned earlier, the CVIS had an established relationship with the selected school prior to this research study; the research site was therefore a suitable choice. In addition, the selected school adhered to the criteria of a government school in South Africa for learners with visual impairments.

In line with the research questions of this research study of limited scope, the following selection criteria were used: as part of purposive sampling participants needed to be parents of children with albinism from a special needs primary school; the focus was on children with albinism in the intermediate and senior phase; parent participants needed to be able to communicate in English; parent participants also needed to provide informed consent; and parent participants had to be available at a time in which learning would not be disrupted. This study of limited scope prioritised depth over width; as a result, four parents of children with albinism were selected to participate in the study. Three of the participants were parents of children with albinism in the intermediate phase and one participant was a parent of a child in the senior phase.

3.4 DATA GENERATION AND DOCUMENTATION

In this section, I discuss the data generation and documentation techniques that were used in the study.

3.4.1 PRA Activities

Participatory methodology includes the collaboration between the researcher and participants in defining the research problem (Ebersöhn et al., 2012). The researchers' aim is to gain new information regarding the topic of research. Participatory Research and Action (PRA) consist of integrated activities involving social inquiry, educational work and action (Ebersöhn et al., 2012). PRA activities usually comprise small group discussions regarding a phenomenon where participants respond to questions using concrete material and engage in visual activities (Chambers, 2002).

In this study, participants were required to synthesise their perspectives as parents on the social justice needs of children with albinism by recording their responses on posters (Willis & Edwards, 2014). While one parent demonstrated their thoughts, beliefs and experiences regarding parental perspectives on the social justice needs of children with albinism, the other parent participants would contribute and synthesise their unique perspectives, one parent participant would then record the information on the poster (Willis & Edwards, 2014).

PRA activities assisted me in contributing to applied concerns of individuals who find themselves in challenging situations, in this case the various situations in which children with albinism find themselves (Ebersöhn et al., 2012). PRA activities further assisted me in confronting challenges resulting from unequal and harmful social systems which in this case were children with albinism who experience various social injustices due to the colour of their skin (Cornish et al., 2023). PRA encourages individuals who experience challenges in society to take action in order to produce social change by conducting organised research to generate new knowledge (Cornish et al., 2023).

A limitation of PRA activities when conducting research is time constraints and a lack of self-confidence from participants in expressing their viewpoints (Ferreira & Ebersöhn, 2011). However, as a result of the relationship that the CVIS has with the school, participants felt secure and trusting of the process and were therefore open to sharing their perspectives regarding the social justice needs of their children with albinism (Ferreira & Ebersöhn, 2011).

3.4.2 Focus groups

Focus groups can include in-depth interviews, ethnographic participant observation and projective methods (Stewart et al., 2015). A focus group comprises a specific group of individuals based on purpose, size, composition and procedures (Krueger & Casey, 2009; Leavy, 2020). The purpose of utilising focus groups is to better understand the way in which a particular group of people think and feel about a certain topic or issue and helps the researcher in gathering various opinions from participants (Krueger & Casey, 2009; Nyumba et al., 2018).

The researcher fosters a permissive environment that encourages participants to share their perceptions and experiences without pressuring participants to vote or reach an agreement (Krueger & Casey, 2009). In this study, the focus group and PRA activities were integrated, where participants could synthesise their perspectives on the social justice needs of children with albinism by discussing the phenomenon in a group and record their responses on the posters.

Focus groups assist the researcher in identifying trends and insights in the participants' perceptions (Morgan, 2019). Focus groups furthermore foster a non-threatening environment where individuals feel comfortable enough to share their experiences, as well as listen to the experiences of others regarding the topic of discussion (Krueger & Casey, 2009). As a result, participants do not feel judged and are able to express themselves freely.

The use of focus groups is often criticised for the lack of spontaneity due to the contexts within which the research takes place, including structured environments. Participants are furthermore mostly aware of what the research is about, which may have an influence on their responses (Morgan, 2019).

3.4.3 Audio-visual data

Audio-visual data collection methods allow the researcher to observe the interaction between participants via multimodal sensing devices which allow the researcher to capture participants' social interactions in the focus groups (Sanchez-Cortes et al., 2012). In order to document data, photographs were taken, and audio-recordings were used to record discussions in the workshop with participants' consent. Audio-visual data permits the researcher to revisit the findings of the study and can further be useful in the analysis of data (Sanchez-Cortes et al., 2012).

The collection of audio-visual data may furthermore assist the researcher in revealing sociological insights that may not be easily accessible (Banks, 2007). Audio-visual data capture the lived experiences of the research situation (Degerbøl & Nielsen, 2014). It is more than a process of documenting what takes place in the data collection, as it assists the researcher in creating knowledge regarding the topic of study and incorporates a multisensory perspective in research (Degerbøl & Nielsen, 2014). In this study of limited scope, I began my data analysis by listening to the audio recordings a number of times and then transcribing the audio recordings to find the intended meaning of the data and to deepen my understanding (Braun & Clarke, 2022).

3.4.4 Observations

Observations are open-ended and allow the researcher to ask general questions which encourage participants to freely express their views and opinions (Denzin & Lincoln, 2017). The researcher then takes field notes pertaining to the behaviour of participants as they answer research questions and engage in discussions. The researcher therefore takes part as an observer thus allowing the researcher to be integrated into the study (Creswell, 2018).

A limitation in relation to this role is the impact of researcher subjectivity as the researcher may enter the participants' natural setting with predetermined notions relating to the subject under study (Creswell & Poth, 2018). As a novice researcher, I equipped myself for encounters relating to the position of an observer. In my role as observer, I took field notes and photographs to ensure that I recorded my observations accurately. Observations took place at the selected research site, namely a government school for visually impaired learners situated in Gauteng, South Africa (Denzin & Lincoln, 2017).

3.4.5 Reflexive journal and field notes

Reflexivity assists the researcher in becoming aware of their biases in the study (Orange, 2016). Reflexivity allows researchers to monitor their responses when responding to clients and helps them consider the way in which their research results are presented (Orange, 2016). According to Braun and Clarke (2022), a reflexive journal allows researchers to reflect upon their own assumptions and the influence they may have in interpreting the data.

Reflexivity furthermore assists researchers in clarifying any conceivable implications of their values, beliefs, and biases. Reflexive journals allow researchers to document their findings and methodological procedures used in the study, which assists them in considering the ethics of their work (Orange, 2016). Moreover, a reflexive research journal allows researchers to track their progress, consider and reflect on their own emotions and document their insights.

Reflexive journals assist novice researchers in documenting their experiences in the data collection and keep track of their mistakes, as well as areas of improvement they have encountered to enhance their interactions in future studies (Orange, 2016). I utilised a reflexive journal to assist me in examining my own biases, assumptions and influences on the research and in my decision-making process regarding the data (Braun & Clarke, 2022).

Field notes assist the researcher in enhancing the data they collected, as well as provide rich descriptions of the study context (Emerson et al., 2011). This includes documenting the sights, smells and sounds experienced in the physical environment (Emerson et al., 2011). The researcher and co-researcher documented the data gathered by taking field notes of the participants' responses and discussions, thus ensuring accuracy in the recording of the data during the workshop.

3.5 DATA ANALYSIS AND INTERPRETATION

Thematic analysis involves a method of identifying themes in qualitative studies (Willig & Rogers, 2017). Thematic analysis is a widely used method of data analysis as it is capable of contributing to rigorous and rich findings in qualitative work (Willig & Rogers, 2017). Thematic analysis involves an active and reflexive researcher; I therefore incorporated reflexive thematic analysis (Braun & Clarke, 2022). Reflexive thematic analysis includes an analytic process based on the researcher's reflective thoughts and engagement with the data. One of the strengths of reflexive thematic analysis is that it allows the researcher to capture intricacies of meaning within the data set (Braun & Clarke, 2022).

Reflexive thematic analysis is furthermore an easily available and ideally flexible interpretative method to qualitative data analysis that simplifies patterns in a data set (Byrne, 2021). Reflexive thematic analysis aligns with interpretivism, as an interpretivist paradigm focuses on people's subjective experiences (Pham, 2018). By applying reflexive thematic analysis, I had the ability to gain a thorough interpretation of parental perspectives and to find meaning in the data set (Braun & Clarke, 2023), which further aided me in addressing my research questions.

Reflexive thematic analysis is often criticised due to the data reduction method in which data patterns are simplified; this consequently offers a low level of interpretation in comparison to other approaches (Braun & Clarke, 2022). As a researcher, I exercised caution when summarising my data findings to avoid low-level interpretations. Using my reflexive journal, I made detailed field notes to avoid over-summarising my findings (Phillippi & Lauderdale, 2017). Field notes assisted me in providing a full interpretation of the findings (Phillippi & Lauderdale, 2017).

A challenge faced in using reflexive thematic analysis is that due to the researcher reading the data through a lens of specific societal, cultural, historic, disciplinary, political, and philosophical positioning, researchers tend to exclude pieces of narrative evidence from the participants’ responses (Braun & Clarke, 2022). Through the use of audio-visual recordings (Bates, 2013), I aimed to capture detailed evidence of participants' responses, therefore avoiding the exclusion of meaningful data.

In phase one, I became engaged in the data by transcribing the audio recordings and then familiarising myself with the data. During this phase, I read the data repetitively in an attempt to find meanings and patterns (Braun & Clarke, 2022). I then examined all the data generation sources as a whole, including my field notes, the PRA-posters, audio transcriptions and my reflexive journal (Creswell, 2016). In my reflexive journal, I made key notes of concepts that were highlighted in the data. In phase two, I started coding by first systematically arranging the key features of the data to find initial codes. During the coding process, I needed to read each item closely in terms of looking for meaning relevant to parental perspectives on the social justice needs of children with albinism (Braun & Clarke, 2022).

Phase three included searching the data for themes (Braun & Clarke, 2022). The data was analysed by colour-coding and merging comparable themes from the initial codes to form themes and sub-themes concerning my research question. The themes and sub-themes that emerged in the data set were compared to the coded material and resulted in thematic maps which conceptualised the data patterns (Terry et al., 2017). The thematic maps assisted me in confirming that the themes were applicable to my research question and also assisted me in representing the generated data in a comprehensive and cohesive manner (Terry et al., 2017).

In phase four, I clarified the emergent themes through an ongoing analysis of the data; I then reviewed the data set (Braun & Clarke, 2022; Terry et al., 2017). In phase five, I defined and named each theme in order to refine the analysed material and to describe the essence of the theme (Terry et al., 2017). In phase six, I produced the report by writing this minidissertation. I selected compelling data extracts that addressed my research question and related to my literature review (Braun & Clarke, 2022; Terry et al., 2017).

3.6 ETHICAL CONSIDERATIONS

In this section, I discuss the way in which I upheld ethical principles in this study of limited scope. I adhered to the University of Pretoria's Code for Ethical Research (University of Pretoria, 2015) and I obtained permission from the Ethics Committee of the Faculty of Education at the University of Pretoria to conduct the research study of limited scope. I also requested approval from the Gauteng Department of Basic Education (GDE). I subsequently requested permission from the principal of the school to carry out the proposed study with parents of children with albinism (Maree, 2016a). This included the approval of the principal, as well as members of the school governing body (SGB).

Participants were not pressured into signing consent forms (Creswell & Creswell, 2017). Participation in the study was voluntarily and the participants were completely knowledgeable about the content and meaning of the consent form before signing the form. It was important that I respected norms and cultures different to my own (Creswell & Creswell, 2017). The way the research had been carried out was done in a manner respectful to the participants' culture. It was also important that I valued the research site and I therefore left the site after the study as I had found it. To do this, I had to minimise disruptions (Creswell & Creswell, 2017).

All participants were involved collaboratively. No participants were deceived in the process, and participants were reminded of the purpose of the study during the process to ensure active participation. Participants were also informed that they could terminate their participation in the study at any time without providing a reason and that there would be no repercussions for terminating their participation (Creswell & Creswell, 2017). It was important that participants' involvement in the study and the topics discussed did not reinforce the stigma that already surrounded the condition of albinism (Bates, 2013).

All audio recordings and photographs were securely stored at the CVIS and are only accessible to members of the research team (Pina et al., 2024). The transcribed data will be stored in a way that will not reveal the identities of the research participants; a number will be assigned to each participant when coding and analysing the data (Pina et al., 2024). No risk of physical or emotional harm to participants was expected during this study (Vos et al., 2011). The parent participants were continuously reminded that they were the experts of the study and that the researchers were therefore merely there to listen to them; as a result, any feelings relating to inferiority were prevented (Yip, 2023).

The participation of the parents in the research study was voluntarily and therefore no monetary compensation or incentives were used to encourage participation (Vos et al., 2011). The study requested the parent participants in a focus group to share their viewpoints regarding the social justice needs of children with albinism; they were able to synthesize their views of social injustices and share common perspectives (Morgan, 2019).

3.7 QUALITY CRITERIA

In this section, I clarify each criterion and provide information regarding the strategies I depended on to improve the quality of this research.

3.7.1 Credibility

Credibility refers to the researcher’s certainty in how true to the research study the findings of the study are. In other words, are the findings obtained from the participants’ original data gathered and is it an accurate analysis of the participants’ viewpoints (Anney, 2014). The purpose of credibility is to ensure confidence in the results, ensuring that the results are true and plausible (Enworo, 2023). This can be achieved through prolonged engagement with the participants, observations, triangulation and allowing the participants to debrief (Enworo, 2023).

Triangulation means utilising a variety of sources of information and procedures to establish identifiable patterns in the data (Stahl, 2020). In this study, the various sources of information and procedures include PRA activities, focus groups, audio-visual recordings, observations, a reflexive research journal and field notes to improve the credibility of data generated (Lincoln & Guba, 1985). I utilised member checking procedures to ensure that the analysed data was accurate. This was done by discussing the findings with the parent participants (Lincoln & Guba, 1985; Motulsky, 2021).

3.7.2 Transferability

Transferability involves the process of transferring the results to other contents and settings. This can be achieved through purposive sampling and reflexivity (Enworo, 2023); meaning that patterns and descriptions from one context can be applicable to another (Stahl, 2020). It is beneficial to seek understanding from others’ systematic qualitative inquiry; this can be done by transferring the data findings from one context to another (Stahl, 2020). The transfer is only possible with thick descriptions that are applicable to other situations. As a result, contextual information regarding the research site needs to be disclosed (Stahl, 2020).

A limitation of transferability is the fact that not all themes that emerged from this study of limited scope necessarily apply to other contexts (Lincoln & Guba, 1985). However, transferability allows the researcher to assess the relevance of the findings to their context by evaluating the context in which the data was generated and the research methodology (Lincoln & Guba, 1985).

3.7.3 Dependability

Dependability ensures that equal outcomes will be obtained if the study was carried out at another time (Enworo, 2023). The research process should therefore be transparent in terms of the processes and procedures followed, while coherence should be ensured across methods and findings (Enworo, 2023). Dependability can be attained through credibility, triangulation, and an audit trail (Enworo, 2023). An audit trail includes all decisions made regarding the methodology and data analysis (Lincoln & Guba, 1985). An audit trail contains the audio-visual recordings, reflexive journal and field notes for external auditors to understand the data processes, and for quality control purposes (Lincoln & Guba, 1985).

Dependability refers to the stability of the findings of the research study over time. This comprises the evaluation of the findings, the way in which the findings are interpreted, and the recommendations offered (Anney, 2014). These findings need to be supported by the data collected from the participants. Dependability can be established through an audit trail, a code-recoding strategy, and peer debriefing (Anney, 2014). An audit trail documenting all the steps, decisions and processes followed by the researcher, was used to confirm the dependability of the study (Lincoln & Guba, 1985). I furthermore utilised the process of peer debriefing, which takes place when another researcher reads and responds to the field notes taken by the primary researcher of the study. This provides the primary researcher with an insider point of view based on analysis and feedback which fosters trust (Stahl, 2020).

3.7.4 Conformability

Conformability demonstrates that the findings and interpretations of the data are not derived from the researchers' imagination and can be linked to the data (Enworo, 2023). An audit trail consists of visible evidence which documents all the processes followed by the researcher (Anney, 2014). Utilising participants' direct quotes in the data analysis will assist the improvement of the neutrality of the research (Kakar et al., 2023). Conformability further relates to the objectivity of the study, which can be achieved by using the appropriate instruments in data generation to control human perception (Kakar et al., 2023). In this study, the reflexive journal was used to compare and confirm the findings of the study with the audio recordings (Lincoln & Guba, 1985).

3.7.5 Authenticity

The authenticity of the research study relates to participants’ fully informed consent, thus ensuring that caring and trusting relationships were fostered during the process. It furthermore relates to all inquiry procedures being transparent to all participants and that full agreement was obtained regarding the rules that govern inquiry and information shared (Amin et al., 2020). In order to establish authenticity, researchers must develop and test their research methods (Shannon & Hambacher, 2015). Researchers furthermore need to engage in processes to ensure that their findings are credible (Shannon & Hambacher, 2015). Fairness should therefore be encouraged where participants are empowered to have a voice and participate in a consensus-building process (Shannon & Hambacher, 2015).

In order to achieve authenticity, the researcher must demonstrate various standpoints and depth of understanding regarding the findings to objectively represent participants' perspectives (Shannon & Hambacher, 2015). Parent participants were able to share their unique experiences of having children with albinism and the difficulties that they faced in society as a result. The information gathered was through face-to-face communication, which improved the authenticity of the data (Lincoln & Guba, 1985). The confidentiality of the participants was furthermore maintained to protect the parents’ identities.

3.8 CONCLUSION

In this chapter, I discussed the paradigmatic perspectives and research methodology, as well as the data generation and documentation techniques that guided the study. I furthermore discussed the data analysis and interpretation methods I employed and subsequently elaborated on the ethical considerations adhered to. I concluded by discussing the quality criteria I applied to ensure the trustworthiness of the study.

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CHAPTER 4 - RESULTS OF THE STUDY

4.1 INTRODUCTION

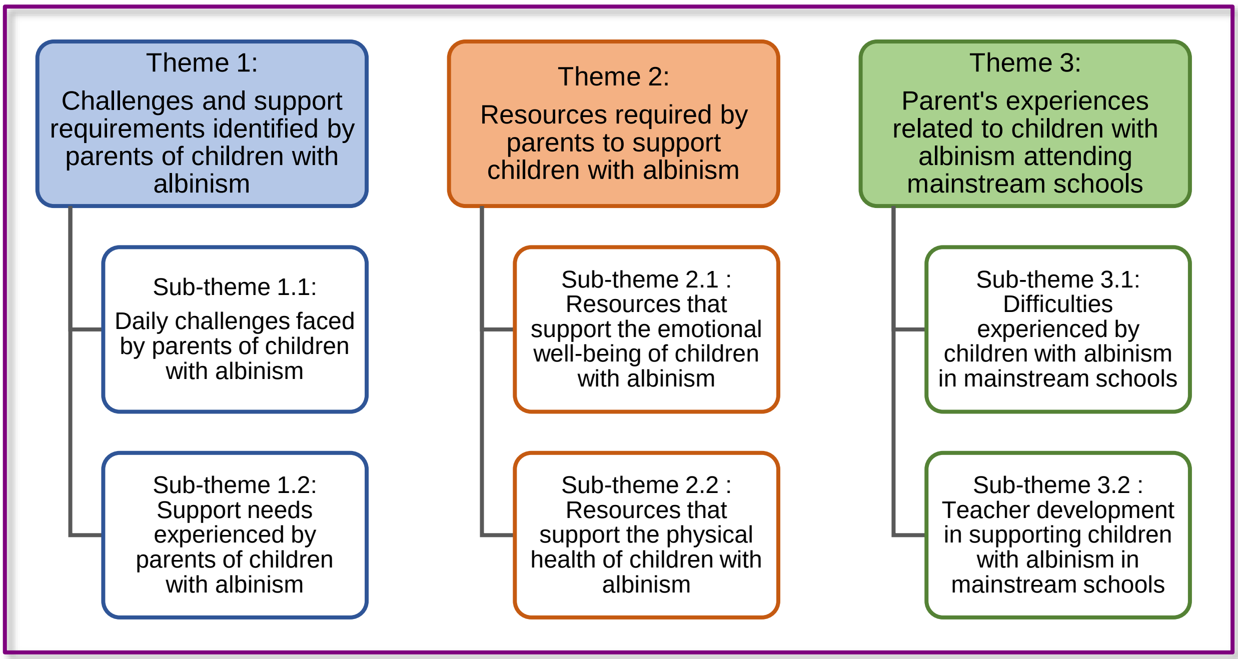
In this Chapter, I present the results of this study of limited scope in terms of three themes and related sub-themes that emerged during the data analysis and interpretation. I then discuss the findings of limited scope against the background of existing literature on parental perspectives of the social justice needs of children with albinism.

4.2 RESULTS OF THE STUDY

In this section, I discuss the results of the study by describing the three themes and associated sub-themes identified during the data analysis.

Figure 4.1

An overview of the themes and sub-themes of the study.



4.2.1 Theme 1: Challenges and support requirements identified by parents of children with albinism

This theme has two sub-themes that capture the experiences, difficulties, and needs expressed by the participating parents of children with albinism. Sub-theme 1.1 presents the ongoing challenges that parents of children with albinism encounter in their day-to-day lives.

Sub-theme 1.2 presents the participants' perceived forms of support and resources identified as essential for managing the challenges experienced by children with albinism.

Table 4.1

Inclusion and exclusion criteria for Theme 1

	INCLUSION CRITERIA	**EXCLUSION CRITERIA**
Theme 1: Challenges and support requirements identified by parents of children with albinism	Data referring to the experiences, difficulties and needs identified by parents of children with albinism.	Data referring to challenges, support systems or resources not related to addressing the needs of children with albinism.
Sub-theme 1.1: Daily challenges faced by parents of children with albinism	Data referring to the day-to-day challenges faced by parents of children with albinism in relation to daily care, decision-making and support regarding albinism.	Data referring to challenges experienced by parents of children with albinism that are not related to the condition of albinism.
Sub-theme 1.2: Support needs experienced by parents of children with albinism	Data referring to the support services experienced by parents of children with albinism including access to health care and educational and social support.	Data referring to parents of children with albinism with comprehensive support systems.

4.2.1.1 Sub-theme 1.1: Daily challenges faced by parents of children with albinism

Parent participants indicated the challenges that they experience in their daily lives as parents of children with albinism, including their concerns about leaving their children with albinism unaccompanied as they fear that the children will be harmed. In this regard, Participant 4 related: *"There are people who murder uhm small children with albinism, kids with albinism because they think they take their parts for muti and other things" (*PRA activities. Participant 4, lines 56-58). Participant 1 indicated the fear of traditional healers as follows: *"Yeah we are so scared maybe our neighbours are a traditional healer, we don't stay there because we are scared"* (PRA activities, Participant 1, lines 541-542). Participant 1 additionally specified: *"Maybe you are in town, or maybe you go somewhere, maybe in the beach. The eyes must always look the kids you didn't enjoy. You spend the time…most of the time to looking the kids"* (PRA activities. Participant 1, lines 97-99). The participants furthermore expressed that as parents they were over-protective towards their children with albinism to prevent them from harm. In addition, it is not easy for the parents to leave their children with albinism in the care of relatives as relatives are often fearful of staying with children with albinism due to safety concerns. Participant 1 revealed:

> *"Even the relatives are scared to stay with them, because I remember the other time I want to go somewhere for a week, I am struggling to get people who's going to stay with my kids. They say, "ah ah ah I'm so scared, I don't have safety… my gate is not locked if someone is come yoh ai ai I am so scared"* (PRA activities, Participant 1, lines 163-166).

The parent participants furthermore revealed that their children with albinism often experience bullying and name-calling from other children. Participant 3 mentioned: *"Sometimes other children call them with names… ugly names"* (PRA activities, Participant 3, lines 139-140). Participant 1 reiterated: *"They tease them with names like your skin is like a chicken. Your skin is like a pork"* (PRA activities, Participant 1, lines 185-186).

Parent participants also mentioned that their children with albinism often question their racial identity by asking their parents: *"Mama are you my real mama? I say agh wena what's wrong? I am your mom. He told me no other kids they told me that me I'm white, you black…which means you are not my mama"* (PRA activities, Participant 1, lines 190-192). As such, the participants mentioned that they often find difficulty in explaining to their children with albinism the reasons for the difference of their skin compared to their parents or other people in their community.

The participants further indicated that every time they go out in public with their children, people stare at their children. Participant 1 mentioned that her children always question her: *"Mama why they look at me?"* (PRA activities, Participant 1, lines 213) when they are seen in public due to individuals staring at them. In some situations, children with albinism are given attention due to their distinctiveness. Participant 1 pointed out: *"Because most of the time when we go and maybe to the mall…can we take a photo with them…can I take a photo with them?"* (PRA activities, Participant 1, lines 216-217). In addition, participants revealed that their children with albinism are often not accepted in the communities where they live and are told to go and live somewhere else. Relevant to this comment, Participant 2 indicated: *"Keep them separate…they are not supposed to live with them"* (PRA activities, Participant 2, line 220). Participant 1 agreed with Participant 2 as follows: *"Because you are* *not like us"* (PRA activities, Participant 1, line 227). This is a common phrase often communicated to children with albinism.

There are various beliefs and superstitions pertaining to the condition of albinism. Participant 1 recounted her experiences of expectoration or spitting by women and young girls on their chests, due to the belief that by expectorating on one's chest, one will not bear a child with albinism. Participant 1 cited: *"Yeah ey mommy you don't know when we are young, we see albinism we just do that"* (PRA activities, Participant 1, line 389).

In addition, parent participants are constantly told that their children with albinism do not pass away under normal circumstances. Participant 2 mentioned: *"And they say when they pass away, they going far to the mountains"* (PRA activities, Participant 1, line 364). Participant 4 further added: *"People believe that children with albinism, they don't die"* (PRA activities, Participant 4, line 408). Related to these statements, Participant 1 revealed a conversation with her child: *"Seven, baby, hai you are young you can't have seven lives. Mom, they say I'm ... I'm as an albinism, I'm like a cat"* (PRA activities, Participant 1, line 420-421).

The participants further pointed out that there is a lack of knowledge in society surrounding the condition of albinism. Participant 1 recounted her experience with a doctor:

> *"The doctor told me that the problem that the children that is teasing your child are the kids, they don't know anything that is why they ask every time, every time they ask because they are the kids, they don't know. You know the kids when you ask them, they need the answer that is going to be suitable for those kids that is why they always ask them why you are white … why this? … why this?"* (PRA activities, Participant 1, lines 296-301).

Regarding the lack of knowledge surrounding albinism, the participants expressed the failure of society to recognise albinism as a disability. Participant 1 expressed: *"So I feel like they didn't recognise their disability of albinism because they treat them with normal people"* (PRA activities, Participant 1, lines 450-451). Participant 1 further elaborated on her experience at a hospital:

> *"He told me, no, we can't treat your children special because they are normal. I said, no, they have a first layer of skin, not a second layer of skin. If you don't know, you must ask me. As a parent, don't tell me that my children, they don't have a disability. You must ask me. Even the sisters, the doctors,*

> *the other doctors, they don't know that the children, they have disabilities. They don't know"* (PRA activities, Participant 1, lines 480-484).

Participant 4 agreed with Participant 1: *"They always say that neh…they always say that"* (PRA activities, Participant 4, lines 517). As a result, the parent participants do not have access to financial assistance in supporting their children with albinism. Participant 4 mentioned: *"SASSA grants or disability grants, let me just say disability grant, they always argue with that, that children with disability they are not disabled"* (PRA activities, Participant 4, lines 525-526).

Participants further stated that the reason why other children often tease their children with albinism is because other parents do not educate their children about albinism; this is due to the parents themselves not being informed regarding the condition. In this regard, Participant 1 stipulated: *"Because the other parent, they can't educate because they don't know about albinism"* (PRA activities, Participant 1, lines 630-631).

The parents further stated their challenge of being first-time mothers to children with albinism. They indicated that they were never really provided with the necessary information regarding the condition of albinism in order to support their children. Participant 1 stated:

> *"Because when I make a research, especially in my place, there's the lack of knowledge. The children, they don't know anything about albinism. Because they didn't even get counselling to tell yourself why your kid is like this. You need doctors, you need people who are educated to tell you about this disability of your kids"* (PRA activities, Participant 1, lines 737-740).

The parents furthermore indicated that they always have questions regarding the condition of albinism:

> *"Because you ask yourself, hey these kids, their eyes are moving. You ask yourself why these eyes are moving. And it's a question and sometimes that's frustrating you. So, I think government can put more efforts. Can put more efforts if you get a child with albinism. To teach this parent, make session with this parent so that they understand clearly"* (PRA activities, Participant 1, lines 745-749).

Participant 3 agreed with Participant 1 and further indicated: *"Because I remember when I got my son, my grandma used to tell me, take him to the sun so that his eyes can stay still,* *not run"* (PRA activities, Participant 3, lines 751-752), thus indicating the lack of knowledge relating to the condition of albinism.

Moreover, the parent participants stated the expenses they incur daily in supporting their children with albinism. Participant 1 explained: *"And to maintain the skin is expensive because the children they must get Vitamin C, Vitamin B"* (PRA activities, Participant 1, line 497). Participant 3 supported the viewpoint of Participant 1 as follows: *"For their cosmetics is expensive"* (PRA activities, Participant 3, line 554). Lastly, Participant 1 revealed the lack of support received from families:

> *"So maybe if you don't have a support maybe in the family, it's not easy to get educated. It's better if maybe you have a husband or you have a parent who can support you. When you ask them, okay let me help you to assist you to get a doctor to work with skin. Let me assist you to get the doctors who work with eyes"* (PRA activities, Participant 1, lines 741-744).

4.2.1.2 Sub-theme 1.2.: Support needs experienced by parents of children with albinism

Parent participants expressed their needs regarding support for their children with albinism. The participants indicated that their children should be treated equally at school. In support, Participant 1 stated: *"And they told me straightly, teacher components say treat children equally"* (PRA activities, Participant 1, line 308). The participants therefore found that their children would feel more comfortable if they were placed in a school where many other learners have albinism. Participant 1 indicated: *"So I get to understand when I look for this school because at least majority of the albinism are here rather in that school"* (PRA activities, Participant 1, lines 318-319). Participant 1 further elaborated:

> *"90 per cent of people with disability are not educated because they didn't finish the school. Because they tease them, tease them, tease them until they don't like the school so they told me the best thing, take your children in there in the school that's are the candidate. Don't take your children and say normal school they must go and and...and...and learn there. I say no, I'm staying far and the school is in Pretoria, they say no if you transport if you stay far, if your children must learn take your children because they are the candidate of that school, I am happy because they are here"* (PRA activities, Participant 1, lines 331-337).

The participants further stated that even in the school that their children with albinism are currently attending, they are teased by other learners. However, this does not bother the participants as their children are surrounded by children who also have albinism. The participants expressed that similarity leads to understanding. However, the parents articulated a desire for their children with albinism to be accepted in all schools. Participant 4 mentioned: *"I'll just say the government should just make the policy that saying the children with albinism should be accepted at any school"* (PRA activities, Participant 4, lines 710-711).

The parent participants further expressed that children with albinism and their parents require support and information relating to the condition of albinism, in order to inform other parents and children about the condition of albinism Participant 1 suggested: *"I think government can assist a lot to get social workers who can deal with albinism. Who can teach that parent with albinism"* (PRA activities, Participant 1, lines 735-740). Participant 4 agreed with Participant 1 that the government should provide training to parents of children with albinism (PRA activities, Participant 4, line 789). Parents expressed a need for their children to be recognised by the government. Participant 4 stated: *"There's this thing called international albinism day"* (PRA activities, Participant 4, line 775). In response, Participant 3 stipulated: *"They don't do anything" (*PRA activities, Participant 3, line 775) to acknowledge individuals with albinism.

Participants conveyed a need for the government to assist them with housing and security, Participant 3 mentioned: *"Maybe let's say, the government should provide them RDP houses. Because in my village, there's a female that's got two children with albinism, and they stay in the shack. You can imagine when it's summer. That house is hot..."* (PRA activities, Participant 3, lines 792-794). Participant 2 further elaborated: *"And then it's going to affect their skin"* (PRA activities, Participant 2, line 796).

4.2.2 Theme 2: Resources required by parents to support children with albinism

In Theme 2, I discuss the resources identified by the parent participants to support children with albinism in terms of healthcare, education, safety and protection. Sub-theme 2.1. presents the various emotional and psychological resources identified by the parent participants to support children with albinism. Sub-theme 2.2. focuses on resources identified by the parent participants to support the physical health of children with albinism.

Table 4.2

Inclusion and exclusion criteria for Theme 2

	INCLUSION CRITERIA	EXCLUSION CRITERIA
Theme 2: Resources required by parents to support children with albinism	Data referring to healthcare, education, safety and protection resources required by parents to support children with albinism.	Data referring to resources required by parents that are not related to supporting the needs of children with albinism.
Sub-theme 2.1: Resources that support the emotional well-being of children with albinism	Data referring to emotional and psychological resources that support children with albinism	Data referring to resources that do not align with the current needs for supporting children with albinism
Sub-theme 2.2: Resources that support the physical health of children with albinism	Data referring to specific physical health needs including sun protection, vision care and skin care.	Data referring to the general physical health needs of children with albinism.

4.2.2.1 Sub-theme 2.1: Resources that support the emotional well-being of children with albinism

Parent participants conveyed that they are the main sources of support for the emotional and psychological well-being of their children with albinism. Participant 1 stated: *"I told myself it's me, they depend on me. I must give them a full support; I must give them everything. When I get those kids, I told myself from today, I am living with albinism, I take the albinism to me…"* (PRA activities, Participant 1, lines 311-316). Participant 1 stated that in order to understand the condition of albinism, and to support and ensure that her children with albinism feel comfortable in their skin, she had to pretend that she had the condition of albinism.

The parents moreover indicated that they provide emotional support to their children with albinism by discussing the condition of albinism with them, including the variances in their appearance in comparison to other children. In this regard, Participant 3 stipulated:

> *"I think hmm by talking to them, I think we are helping them 'cause my child when he was two years old, I used to tell him that, baby, you are different from us. Your skin is light, and you are beautiful like that, and I took her to the nanny. There were five kids and six with him. Then I explained to him that*

> *now I'm going back to work, and I'm going to leave you with the nanny. You must just know that you are different. There's nothing wrong with you. Your skin is light and beautiful. Then it gave him confidence, even though they called him like, "Umlungu" he didn't get upset because I already told him that you are beautiful, your skin is very, very beautiful"* (PRA activities, Participant 3, lines 579-586).

Participant 4 agreed with Participant 3 by stating: *"Parents should educate their children about their disability"* (PRA activities, Participant 4, lines 617).

The participants further agreed that they provide support to their children with albinism by displaying affection, Participant 4 reiterated: *"Support meaning by always giving them support, showing them love"* (PRA activities, Participant 4, lines 588-589). Participant 1 mentioned that when she has the financial means, she spoils her children as a reminder of her love for them: *"But most of the time when I have money when I take them out, they see, hey, mama is protecting us. Mama loves us. You, see? And always tell them, I love you, I love you, I love you"* (PRA activities, Participant 1, lines 601-603).

The participants further indicated the importance of praying for the well-being of their children. In this regard, Participant 1 stated: *"Exactly…and pray hard for them because this situation needs prayers. Because most of the time when I pray for my kids, I say, I don't have powers, but God has a power on your lives…"* (PRA activities, Participant 1, lines 591-592).

Lastly, the parent participants expressed the importance of education. The participants indicated that in order for children with albinism to access resources to assist them with their condition, they require an education that enables them to secure jobs. It is therefore important for parents of children with albinism to motivate their children to pursue an education. Participant 1 mentioned: *"I say the best thing in your life, you must get education. Because your disability needs a proper education, it needs money. If you don't have money, you struggle to stay in this world"* (PRA activities, Participant 1, lines 610-612).

4.2.2.2 Sub-theme 2.2: Resources that support the physical health of children with albinism

The parent participants all agreed that they support the physical well-being of their children with albinism by purchasing essential items that protect their children from the sun's rays. In terms of nutritional requirements, Participant 1 expressed that her children with albinism require a well-balanced diet rich in vitamins and minerals for skin health. She stated: *“I must make sure that every week, twice a week they eat eggs and cheese and milk to balance the skin because they told me if they didn’t eat those things their skin is going to be dry”* (PRA activities, Participant 1, lines 558-560). Since children with albinism usually avoid exposure to the sun, they tend to have a vitamin D deficiency. Parents of children with albinism therefore need to ensure that their children receive the required vitamins through their diet.

The parent participants additionally indicated that they are required to purchase cosmetics and protective clothing, which can be expensive, for their children with albinism. Participant 1 stated: *“I buy many stuff. The hats, I buy the hats maybe four times or five times a year”* (PRA activities, Participant 1, lines 461-462). Participant 3 agreed with Participant 1 by mentioning: *“It's going to peel”* (PRA activities, Participant 3, line 562). Participant 1 indicated the importance of protective sunglasses: *“They must also wear sunglasses. When they go maybe in the sun, wear sunglasses. And those sunglasses we must buy. Always, always”* (PRA activities, Participant 1, lines 653-654). Participant 4 agreed with Participant 1 and added: *“children with albinism should wear their glasses and sunscreen when they go to the sun. And also protect themselves with a hat and umbrella”* (PRA activities, Participant 4, lines 656-657).

The participants agreed that children with albinism require sunscreen and aqueous cream, stating that these products are usually received from local hospitals. However, the parents mentioned that their local hospitals are often out of stock, which means that they have to purchase the products from their own pockets. Parents of children with albinism also have to purchase food, protective clothing, sunscreen and umbrellas to safeguard the physical well-being of their children with albinism.

The parent participants furthermore stated that they inform their children with albinism about the risks of being exposed to the sun. *Participant 1 mentioned: “Give them the reason why you're not exposed to the sun because your skin is light”* (PRA activities, Participant 1, lines 644-645). Participant 4 agreed with Participant 1 and elaborated: *“It can harm their skin”* (PRA activities, Participant 4, line 647).

4.2.3 Theme 3: Parents’ experiences related to children with albinism attending mainstream schools

In Theme 3, I discuss the parent participants' experiences regarding children with albinism attending mainstream schools. These experiences include interaction with teachers, peers and school management. Sub-theme 3.1. presents the social and academic challenges experienced by children with albinism in mainstream schools. Sub-theme 3.2. focuses on teachers' professional development in relation to children with albinism in mainstream schools, including visual impairment adaptations, sensory needs and social and emotional support.

Table 4.3

Inclusion and exclusion criteria for Theme 3.

	INCLUSION CRITERIA	EXCLUSION CRITERIA
Theme 3: Parent's experiences related to children with albinism attending mainstream schools.	Data referring to parents' experiences related to children with albinism attending mainstream schools, including interaction with teachers, peers and school management.	Data referring to parents' experiences in non-mainstream schools.
Sub-theme 3.1: Difficulties experienced by children with albinism in mainstream schools	Data referring to social and academic challenges experienced by children with albinism in mainstream schools	Data referring to difficulties experienced by children with albinism in non-mainstream schools
Sub-theme 3.2: Teacher development in supporting children with albinism in mainstream schools	Data referring to teacher professional development regarding children with albinism in mainstream schools, including visual impairment adaptations, sensory needs and social and emotional support.	Data referring to teacher professional development not related to supporting children with albinism in mainstream schools.

4.2.3.1 Sub-theme 3.1: Difficulties experienced by children with albinism in mainstream schools

The participants indicated the lack of support they have received from mainstream schools in assisting their children with albinism. In this regard Participant 3 stipulated:

> *"Mine would be when you take an albino child to normal school, like sometimes he or she is going to face challenges with the teachers and the kids will be bullying them and the teachers will not, and some of the teachers*

> *will not like accept them like other kids"* (PRA activities, Participant 3, lines 238-241).

Participant 3 further elaborated that her son used to write out of the line; she explained: *"They didn't give him special treatment, no you must write on this line. They just say wrong"* (PRA activities, Participant 3, lines 255-256). Participant 1 revealed her experience in a mainstream school by mentioning:

> *"That principal told me that we make a favour to take the children in our school because they didn't belong to our school, in our school. They explain to me that I've got 94 children in Grade R and 96 children in grade R are black, only two are white. It's a big challenge for me as a principal, because I … I go to learn to teach the child, I didn't go to learn to discuss the condition with the child… I think you must go to the social workers and tell the social workers that my kids are attending in this crèche, so that at the social worker they will go to that crèche and address the children about these two kids"* (PRA activities, Participant 1, lines 238-289).

The above comments illustrate the lack of knowledge surrounding the condition of albinism and the non-acceptance of children with albinism in mainstream schools.

To gain acceptance for her children with albinism at mainstream schools, Participant 1 sought help from a doctor and a social worker. Participant 1 indicated her experience with the doctor as follows:

> *"The doctor says, don't worry, I am going to call the principal, I am going to use the strategy so that the children can just get the school. He call the principal he say to the principal, okay as a doctor I am going to buy fancy things for those twins so that the children will come and pay attention for them. So it means we buy love for them, because when they see maybe they playing with this they'll say, hey can I see, can you please borrow me? They seem like they accepted"* (PRA activities, Participant 1, lines 301-306).

Participant 1 thus indicated that in order for her children with albinism to gain acceptance in a mainstream school, the situation requires that love and acceptance must be bought. Participant 1 indicates her experience with the social worker as follows:

> *"When I call the social work, I ask the social worker, my kids are at the crèche and the principal say you must go and visit the créche and tell the crèche*

> *about the children. They say no, come in the office. I came, the social worker they told me, that, even if I go there, maybe your kids are going to be sensitive when I take the kids and put in front of all the children, maybe they lose their self-esteem, maybe they will lose the self-esteem. It's difficult even to me to take the kids and show the other kids, you know this kids are living … are wearing this this. It's difficult for me as a social worker I didn't say I don't want to help you but it's difficult, because when I do that, maybe sometimes they lose the self-esteem and they told me that social worker, 90 per cent of people with disability are not educated because they didn't finish the school. Because they tease them, tease them, tease them, until they don't like the school, so they told me the best thing, take your children in there in the school that's are the candidate"* (PRA activities, Participant 1, lines 323-334).

Participant 1 was therefore advised by the social worker to take her children with albinism to a special school that caters for children with albinism, in order to avoid her children from being discriminated against. Participant 4 agreed with this by stating: *"They are facing discrimination at the normal schools"* (PRA activities, Participant 4, line 274).

4.2.3.2 Sub-theme 3.2: Teacher development in supporting children with albinism in mainstream schools

The parent participants all agreed that teachers should undergo training regarding how to assist children with albinism in the classroom. The participants also agreed that the government should provide training to teachers regarding the condition of albinism. Teachers need to be aware of the causes, physical characteristics and challenges children with albinism face, including visual challenges and skin sensitivity. In this regard, Participant 4 mentioned:

> *"The teachers as well they should also be trained. Because some people they don't know that a child with albinism must sit in front. And they also they don't know that they should also use a big font when they are giving notes or something"* (PRA activities, Participant 4, lines 862-864).

Participant 2 agreed with Participant 4, stating: *"Must get trained about albinism"* (PRA activities, Participant 2, line 875). It is important for teachers to understand the need for children with albinism to sit in front of the classroom to see the writing board. They should also be placed away from windows where the sun shines in to avoid damage to their skins.

Due to children with albinism being sensitive to bright light, the colour of white on a chalkboard can make it difficult for them to see, especially if there is a glare on the chalkboard. In this regard the participants indicated the importance of teachers being aware of the colours that should be used on the chalkboard when teaching children with albinism.

In this regard Participant 3 asserted: *“...and not using a colour white on the chalkboard because it's too bright for them. I think they should use different colours when they write on the board”* (PRA activities, participant 3, lines 866-867). Participant 4 agreed by stating: *“... they must use other colours on the chalkboard except white. Different colours neh”* (PRA activities, Participant 4, lines 882-883).

Lastly, the participants indicated that teachers in mainstream schools often do not accept children with albinism. They also indicated the need for teachers to treat children with albinism fairly. Participant 4 stipulated: *“Teachers, they should just treat them fairly at school. Like any other kids.”* (PRA activities, Participant 4, line 855). If teachers are trained to be aware of the challenges faced by children with albinism, they will be able to accept children with albinism and accommodate them in mainstream schools.

4.3 FINDINGS

In this section, I discuss the similarities and contradictions of the findings of this study of limited scope in relation to existing literature regarding parental perspectives on the social justice needs of children with albinism.

4.3.1 Parental perspectives on challenges and support needs for children with albinism

The findings of this study of limited scope indicate that children with albinism experience various challenges relating to social and emotional difficulties, educational barriers, health and safety concerns, exclusion and cultural challenges. This viewpoint correlates with the findings of Lynch et al. (2014) and Tambala-Kaliati et al. (2021) which indicate that individuals with albinism experience various difficulties in terms of financial constraints, health complications, a lack of support from communities and being subject to superstitious beliefs.

The parent participants affirmed that they can never leave their children unaccompanied or in the care of others due to the fear that their children with albinism may be harmed. The parents were told that there are people who kill children with albinism for their body parts to use for traditional treatments. Bradbury-Jones et al. (2018) confirm that children with albinism are often targeted for their body parts, which are used in witchcraft-related rituals; this is due to the belief that the body parts of children with albinism can generate wealth and good fortune. Children with albinism are therefore attacked in various ways, including forcibly shaving their hair, mutilating their fingers, limbs, ears and genitalia and killing them (Bradbury-Jones et al., 2018; Cruz-Inigo et al., 2011). Franklin et al. (2018) state that parents of children with albinism are prone to hiding their children at home or seeking asylum at police stations or other areas of safety. Owoeye et al. (2023) furthermore asserts that in some communities, parents escort their children to and from school due to the fear of harm and kidnapping. Some parents of children with albinism moreover migrate to safer parts of the country to protect their children (Franklin et al., 2018).

In addition, the parent participants indicated that their children with albinism often experience bullying and name-calling from other children, who are ignorant about albinism an therefore tend to question the racial identity of children with albinism. Franklin et al. (2018) agree that due to a lack of pigmentation in the hair and skin of children with albinism, their appearance makes them stand out among African communities, resulting in their racial identity being questioned. Cruz-Inigo et al. (2011), concur that in a school in Zimbabwe, children with albinism faced name-calling, beatings and isolation by peers because of their pale skin colour.

Another challenge experienced by parents of children with albinism is the difficulty of explaining the condition of albinism to their children. According to Baker et al. (2010), there is a general lack of knowledge surrounding the special care that children with albinism require to function in their daily lives. Dufresne et al. (2021), state that due to a lack of knowledge about albinism, some parents regard albinism as a specific trait rather than a disease. Most parents of children with albinism additionally experience anxiety when their child is born and diagnosed as having albinism since they tend to feel helpless (Dufresne et al., 2021). Education is therefore the only way that parents can come to understand the condition of albinism and find ways of supporting their children.

Parent participants further indicated that their children with albinism are often not accepted in the communities where they live; they are therefore told by community members to leave the community and live elsewhere. Aborisade (2021) confirms the rejection of communities of children with albinism by describing the experience as *othering*. This involves individuals in Sub-Saharan Africa who perceive children with albinism as outsiders in black African communities and therefore reject them (Aborisade, 2021). Bradbury-Jones et al. (2018)

support this finding by stating that the segregation of children with albinism begins during the early years of life.

The findings of this study indicate that the condition of albinism is subjected to various myths, including the expectoration on one's chest to prevent the birth of a child with albinism. In addition, the belief that children with albinism do not die, but disappear far away to the mountains, or that children with albinism have seven lives and can thus be compared to that of a cat with seven lives. Baker et al. (2010) confirms the myth that children with albinism do not experience a normal death, but rather go to the bush and disappear.

Baker et al. (2010), furthermore affirm that in the Venda region of South Africa, there is a belief that spitting inside one’s shirt wards off the contagion of bearing a child with albinism. Similar practices include holding one's hair and turning away from an individual with albinism. Franklin et al. (2018) furthermore indicate that myths and superstitions caused by a lack of understanding of the condition of albinism, as well as the different skin colour of children with albinism compared to other family and community members, lead to discrimination and rejection. Due to their pale skin colour, children with albinism are viewed as a white person within a black community.

The findings of the study indicate that one of the major challenges experienced by parents of children with albinism is the lack of communication and information regarding the condition of albinism, which leads to insufficient support from society. Likumbo et al. (2021) confirm that beliefs surrounding albinism in southern Africa are due to inadequate knowledge about the condition and it is therefore misunderstood. According to Nebre (2018), public awareness is required to stop the harmful and violent actions against children with albinism.

Daklo and Obadire (2024) agree that to prevent attacks on and violations of the human rights of children with albinism, a multi-faceted approach is necessary. This includes education as one of the most effective ways to reduce discrimination against children with albinism (Daklo & Obadire, 2024). Educating societies about the condition of albinism will raise awareness in terms of the causes and effects of albinism. As a result, the myths and misconceptions regarding albinism can be diminished (Daklo & Obadire, 2024). This should lead to a wider understanding and acceptance of children with albinism.

Children with albinism require various healthcare products and care to assist them with their condition. As a result, parents of children with albinism incur additional expenses. According to Baker et al. (2010), children with albinism require protective clothing, sunscreen and visual aids on a daily basis. In addition, Taylor and Lund (2008) mention that children with albinism tend to get skin cancer, which requires expensive treatment. Taylor and Lund (2008) further mention that some guardians of children with albinism cannot afford sunscreen and other medication to treat their skin. Udeh et al. (2013) affirm that parents of children with albinism face socio-economic burdens as a result of their child's condition and although this financial burden may be lower in comparison to other health problems, parents still face difficulty in treating the condition.

4.3.2 Parents' need for guidance and support on the condition of albinism

The findings of this study of limited scope indicate that parents of children with albinism require substantial support from the South African government. Parents have indicated that the government should have policies in place that promote the acceptance of children with albinism in all schools in South Africa and that the government should train teachers regarding the condition of albinism. Tambala-Kaliati et al. (2021), assert that children with albinism do not receive assistance or support from teachers due to a lack of suitable training of teachers in how to deal with the needs with of these children.

Teachers who do have knowledge of albinism are able to assist children with albinism and as a result, enhance their self-esteem and create a sense of belonging (Franklin et al., 2018). According to Kromberg et al. (2020), if teachers are made aware of the social issues that children with albinism experience, they will be better equipped to create an inclusive environment for children with albinism by fostering equality and creating awareness of the condition.

The findings of this study furthermore indicate that the government should employ social workers that are educated about the condition of albinism to provide information and guidance to parents of children with albinism. Franklin et al. (2018) affirms that if the condition of albinism is not understood, it can have adverse health-related effects and social consequences for children with albinism. It is therefore important that parents and caregivers of children with albinism are informed about the condition and ways of supporting their children both physically and emotionally.

According to Kromberg et al. (2020), when children with albinism grow up and start socialising with other children, they are likely to experience discrimination, isolation and rejection from those children. However, children who do not have the condition of albinism may be partially accepting of children with albinism if they are aware that a child with albinism is no different to themselves (excluding skin variations and visual impairments) (Kromberg et al., 2020). Tambala-Kaliati et al. (2021) point out that parents' lack of knowledge about albinism negatively affects the way in which families take care of their children with albinism. Families therefore need to be informed about ways to care for their children with albinism.

The findings of this study confirm that government should acknowledge children with albinism in society and assist in recognising the condition of albinism as a disability. According to Taylor et al. (2019), the recognition of albinism as a disability is increasing in Sub-Saharan Africa. This is due to the significant visual impairments and high fatality rates as a result of skin cancer relating to the condition of albinism (Taylor et al., 2019).

According to Cruz-Inigo et al. (2011), government organisations are isolated and therefore do not include an integrated and comprehensive healthcare system for children with albinism. As a result, a lack of awareness and education regarding the condition of albinism is tied with ignorance. Cruz-Inigo et al. (2011) affirm that many children with albinism in Sub-Saharan Africa face a lack of proper healthcare, and ignorance about their condition in their communities.

Parents participants in this study have indicated that the government should provide health care resources and housing to assist children with albinism with their healthcare needs. Franklin et al. (2018) indicate that children with albinism have the right to access proper healthcare, including access to vision healthcare and skin protection products due to the high risk of children with albinism developing skin cancer. Cruz-Inigo et al. (2011) confirm that government agencies should provide sun-protection resources to parents of children with albinism and should fund organisations that promote albinism awareness and support among the wider public.

4.3.3 Parents' recommendations for resources to support the emotional and physical well-being of children with albinism

The findings of this study of limited scope indicate that parents of children with albinism are the main, if not, only sources of support for children with albinism. Parents have indicated that they not only support their children with albinism financially, but also emotionally with love and affection; this reassures their children that even though they are different and may experience discrimination in society, they are loved by their parents.

Mukuna and Machingambi (2023) confirm the importance of parents and families of children with albinism in building resilience in response to the adversities they experience. Mukuna and Machingambi (2023) further emphasise the importance of parents in the education system, because parents understand the physical, social and developmental history of their children with albinism. In addition, parents can assist with the development of Individualised Educational Plans (IEP) to ensure academic achievement and social adjustment. However, according to Franklin et al. (2018), many children with albinism are raised without the support of both their parents and therefore do not receive the love and support of both their parents.

Parents participants in this study have indicated that they support their children with albinism by explaining the condition with their children. Parents further indicated that they tell their children with albinism that the only difference between them and other children is the colour of their skin. In addition, parents have indicated that they support the physical well-being of their children with albinism by informing them that their skin is sensitive to exposure to the sun and susceptible to skin cancer. For children with albinism to avoid the risk of developing skin cancer, they should be taught how to implement effective sun protection from a young age (Franklin et al., 2018).

The findings of this study have furthermore indicated that parents of children with albinism support the physical well-being of their children by purchasing skincare items to assist them with their skin conditions. Tambala-Kaliati et al. (2021) affirm the importance of parents being knowledgeable about how to care for their children with albinism, including the correct use of sunscreen, wearing protective clothing, and wearing sunglasses to protect their eyes.

According to Franklin et al. (2018), children with albinism have the right to education and therefore teachers in mainstream schools need to ensure that they understand their needs The findings of this study of limited scope indicate that parents believe that their children with albinism should be accepted in all schools in South Africa, including mainstream schools through the assistance of the government. However, the findings further indicate that children with albinism are not catered for or suitably assisted by teachers in mainstream schools. As a result, children with albinism are better off if they attend special needs schools.

According to Ndomondo (2015), most children with albinism in South Africa should be able to attend special needs schools for the visually impaired. Ndomondo (2015) asserts that in countries such as Malawi, the government has created resource centres to train teachers in supporting visually impaired learners including children with albinism.

4.3.4 Parents' recommendations for teacher development in supporting children with albinism

The findings of this study of limited scope indicate that teachers should undergo training in order to support children with albinism in schools and be able to cater for their various learning styles. Daklo and Obadire (2024) assert that most teachers are unwilling to support the needs of children with albinism due to ignorance about the condition. This results in high dropout rates and low academic performance of children with albinism. According to Kromberg et al. (2020) if teachers are trained to support children with albinism, these children will be able to attend mainstream schools. Owoeye et al. (2023) suggested that teachers require specialised knowledge relating to the condition of albinism, including the ability to utilise educational aids such as braille texts, resources and equipment required by visually impaired learners in order to encourage maximum participation of children with albinism in the classroom.

Parents of children with albinism have further indicated that teachers need to be aware of the seating arrangements in the classroom and ensure that children with albinism are seated in front of the classroom near the chalkboard or whiteboard. Kromberg et al. (2020), confirm the necessity of teachers knowing that children with albinism need to sit in front of the classroom and need to be able to walk to the chalkboard if required. In addition, visual aids should be encouraged, and children should be seated away from any glare in the classroom. Tambala-Kaliati et al. (2021), recounted experiences of children with albinism who were not able to see from the chalkboard during teaching as a result of their visual impairments, however, their peers were able to see the chalkboard without any difficulty. According to Ndomondo (2015), children with albinism may require extra time to finish their work and assignments that teachers need to accommodate. Ndomondo (2015) states that these are affordable measures which require teachers to gain knowledge about the needs of children with albinism.

Furthermore, parents of children with albinism indicated that teachers need to be mindful of the colours that they use on the chalkboards as some colours can be difficult to see for a child with albinism. Teachers can support the learning needs of children with albinism by making minor adaptations to the classroom thus ensuring access to visual aids. (Franklin et al., 2018). According to Thwala et al. (2021), some children with albinism may struggle to see on the writing board and therefore it will be beneficial to them if teachers could utilise hand-outs instead of writing on the board. By providing hand-outs, children with albinism can focus on the work being taught instead of moving around in attempts to see on the board which may disrupt their learning (Thwala et al., 2021).

4.4 CONCLUSION

In this chapter, I discussed the results and findings of this study of limited scope. I first explored the challenges and support requirements identified by parents of children with albinism. Secondly, I explored the resources required by parents to support children with albinism. Thirdly, I presented the theme of parents' experiences related to children with albinism attending mainstream schools and finally, I compared the findings of this study of limited scope against existing literature on parental perspectives on the social justice needs of children with albinism.

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CHAPTER 5 - CONCLUSIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In this chapter, I conclude my study of limited scope by addressing the research questions I formulated in Chapter 1. I further discuss the potential contributions, challenges, and limitations of this study and conclude with recommendations regarding practice and opportunities for further research.

5.2 OVERVIEW OF PRECEDING CHAPTERS

In Chapter 1, I provided an overview of the study by first introducing the rationale and purpose for undertaking this study of limited scope. I then presented the primary and secondary research questions that guided the study. I clarified the key concepts of the study and provided a brief introduction of the theoretical framework, as well as the epistemological and methodological paradigms I utilised. This was followed by an overview of the research design, data generation and data analysis methods. I concluded the chapter by stating the ethical guidelines and the quality criteria I adhered to in the study.

In Chapter 2, I explored existing literature relating to parental perspectives on the social justice needs of children with albinism. I focused on albinism in Southern Africa, and challenges typically experienced by children with albinism. I discussed national efforts to address the associated challenges of children with albinism. In addition, I explored literature regarding parents' perspectives on the social justice needs of children with albinism and ways of addressing the needs of children with albinism. I concluded the chapter by discussing the theoretical framework that guided my study.

In Chapter 3, I presented the paradigmatic perspectives, methodology, ethical considerations and quality criteria used in this study, followed by a discussion of the interpretivist paradigm and the qualitative research approach. I subsequently presented the research methodology, namely an intrinsic case study research design and the purposive and convenience sampling methods utilised. In addition, I discussed the data generation methods I used, including PRA activities, a focus group, audio-visual recordings, field notes, observations and a reflexive journal. I furthermore stated the ethical considerations I adhered to. To conclude, I presented the qualitative quality criteria I followed.

In Chapter 4, I presented the results of this study of limited scope according to the three themes and subthemes I identified through reflexive thematic analysis. I subsequently discussed the findings of the study of limited scope and provided my interpretation of the results against the background of contemporary literature, highlighting the similarities and differences.

5.3 CONCLUSIONS

In the following subsections, I present the conclusions of this study of limited scope by addressing the three secondary questions and lastly, the primary research question formulated in Chapter 1.

5.3.1 Secondary research question 1: *Which social justice challenges are experienced by children with albinism in South Africa (as perceived by their parents)?*

This study was aimed at exploring and describing parental perspectives on the social justice needs of children with albinism. The results indicate that children with albinism experience challenges in various contexts, including social, educational, cultural, political and healthcare settings. According to the parent participants, children with albinism often experience name-calling, teasing and bullying due to the unique features associated with their condition.

The results furthermore indicate that children with albinism are often targeted and killed for their body parts as a result of ethnic rituals due to misinformation. The body parts of children with albinism are often used in witchcraft-related activities or for traditional healing purposes. Furthermore, in social settings, children with albinism are stared at and questioned about their skin colour.

The results also indicate that children with albinism are not accepted or accommodated in mainstream schools. This forces parents to remove their children from mainstream schools and seek special needs schools where their children can meet and interact with other children who have albinism. The result is that children with albinism find a sense of belonging in special needs schools. Parent participants additionally indicated that children with albinism are often rejected in communities and they and their families are told to go and live somewhere else.

According to the parent participants, due to cultural beliefs and superstitions, young women spit on their chests at the sight of a child with albinism to prevent them from bearing a child with albinism. Children with albinism are furthermore led to believe that they do not die and that they have as many lives as a cat. The results also indicate, according to parent participants, that due to a lack of knowledge of the condition of albinism, society fails to recognise albinism as a disability. As a result, there is a shortage of healthcare resources provided by the government to support children with albinism. In addition, the government do not have policies in place that regard albinism as a disability.

5.3.2 Secondary research question 2: *What is the role of parents in relation to the social justice needs of children with albinism?*

The results of the study indicate that due to the fear that their children with albinism will be harmed, parents of children with albinism live with constant anxiety about their children's safety, causing them to be overprotective. According to the parent participants in this study, they need to constantly look out for their children in social settings and do not want to leave their children unaccompanied or in the care of others. Parent participants have furthermore indicated that they make sure not to live close to a traditional healer in order to protect their children with albinism.

Because children with albinism are moreover often questioned about their appearance, their parents have to explain the condition of albinism to their children. Parent participants indicated that they needed to remind their children that besides the variation in their skin colour, there are no differences between children with albinism and other children.

The results of the study further indicate that parents have to find special needs schools, that are often located far from where they live, to accommodate the needs of children with albinism. Parent participants also indicated that they support their children by advocating for children with albinism, thus creating awareness about albinism and informing others about the implications of the condition. In addition, parents support their children by informing them of the dangers of the sun’s rays and the need for protection; they purchase protective clothing and sunscreen to shield their sensitive skin, and provide food that supplements their diet, ensuring that they get the required vitamins and minerals to boost their immune system.

5.3.3 Secondary research question 3: *Which strategies can be utilised to support the social justice needs of children with albinism (according to their parents)?*

The results of the study indicate that parents should also support their children with albinism emotionally by displaying affection towards them and reminding them that they are loved. In addition, parent participants indicated that other parents should inform their children with albinism about the health implications of their condition, for example, the dangers of the sun's rays on their skin and the need for protection. The results of the study furthermore indicate that the government should provide training to parents regarding the condition of albinism so that parents can support their children with albinism effectively. Parent participants also indicated that the government should acknowledge the condition of albinism as a disability as this may raise awareness of the condition of albinism in society.

The results of the study moreover indicate that for children with albinism to be accepted in mainstream schools, parents require assistance from various role-players, including the government, healthcare providers and social workers. Parents indicated that the government should train teachers in mainstream schools on how to accommodate and assist learners with albinism. This includes knowledge relating to the seating arrangements of children with albinism in the classroom such as seating them close to the chalkboard, providing reading materials with large easy to read fonts and avoiding the use of the colour white on chalkboards.

Parents additionally require the assistance of doctors and social workers to explain the condition of albinism to learners and teachers in mainstream schools, so that their children with albinism will be accepted. The parents moreover suggested that the government should employ social workers to assist parents with knowledge on how to support their children with albinism. Lastly, according to parent participants, the government should increase the provision of sunscreen and other skin products required by children with albinism at no cost at healthcare facilities.

5.3.4 Primary research question 1: *How do parents perceive the social justice needs of children with albinism?*

Based on the findings of my study, I can conclude that parents have various perspectives on the social justice needs of children with albinism. These perspectives are shaped by their social experiences, cultural contexts and the challenges their children with albinism face as a result of their condition. Parents of children with albinism see a need to often advocate for their children's rights, including social acceptance and the prevention of bullying and name-calling, as well as access to education, healthcare, safety and security. Parent participants indicated that they prioritise the social justice needs of their children with albinism ensuring that they are protected by placing them in special needs schools, relocating to safer areas to live and providing physical and emotional support.

The results further indicate that parents require substantial support in addressing the social justice needs of children with albinism. This includes the support of various role-players, such as the government, teachers, healthcare providers and social workers. The results suggest that parents of children with albinism have a need for social justice for their children, such as the inclusion of their children in society through increased awareness and sensitivity within communities to reduce discrimination and foster acceptance of children with albinism.

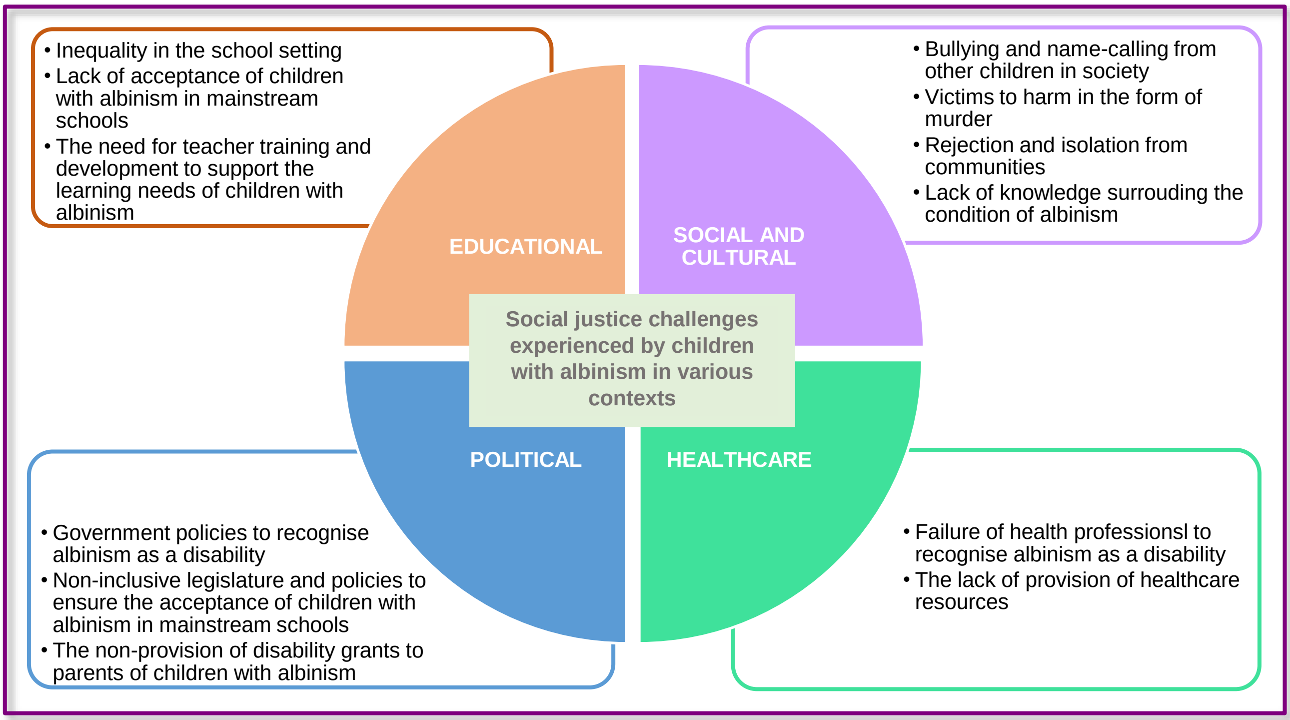
Regarding access to education in mainstream schools, parents identified the need for teacher training in terms of accommodation and visual aids. Moreover, parents of children with albinism perceive the condition of albinism as a disability that should be recognised in society to enable access for children with albinism to healthcare resources.

Lastly, parents perceive beliefs and superstitions about the condition of albinism as ignorance and a lack of accurate knowledge regarding albinism. The aforementioned highlights the aspects of the social model of disability (Oliver, 2013); this model emphasises that disability is not merely a result of an individual's physical condition, but rather the effect of societal barriers including lack of knowledge, discrimination and social exclusion.

According to the social model of disability (Oliver, 2013), the objective is to change society’s perspectives to accommodate individual differences, instead of trying to change the individual with a disability. Parents of children with albinism therefore perceive the challenges faced by their children through a lens of social justice, which aligns with the social model of disability. Parents of children with albinism acknowledge that the challenges faced by their children are not exclusively related to their condition of albinism but instead are intensified by societal barriers. Through advocating for awareness of albinism, acceptance of children with albinism in mainstream schools, and the recognition of albinism as a disability, parents of children with albinism seek a societal shift that the social model of disability promotes. Parents therefore aim to promote the inclusion of their children with albinism in society instead of pursuing solutions to health challenges.

Figure 5.1

The findings of this study in relation to the social model of disability (Oliver, 2013)



5.4 POTENTIAL CONTRIBUTIONS OF THE STUDY

As far as I am aware, through searches of peer-reviewed databases, it was found that no preceding studies have explored parental perspectives on the social justice needs of children with albinism in the South African context. While literature does exist on the experiences of children with albinism, access to education and social inclusion, as well as the experiences of mothers of children with albinism, the current study contributes to parents' perspectives on the social justice needs of children with albinism, including support from various role-players and access to resources. Furthermore, the available literature does not indicate the significant role of mothers of children with albinism in advocating for their social justice needs. This study therefore contributes to insight into parental perspectives on the social justice needs of children with albinism.

Based on the diversity of the country, the South African context varies from other African countries. Most Sub-Saharan studies relating to the rights of children with albinism are based on contexts including countries such as Tanzania, Zimbabwe, Malawi and Nigeria. This study, therefore, extends the limited research in South Africa by providing context-specific insight into parental perspectives, as well as the challenges and resources required to address the social justice needs of children with albinism.

As mentioned in Chapter 1, this study of limited scope formed part of a broader research project within the CVIS at the University of Pretoria. The focus of the broader research project is on strengthening social justice for children with albinism with the objective of facilitating social change and equal opportunities for children with albinism as an outcome.

5.5 CHALLENGES AND POSSIBLE LIMITATIONS

As a result of this being a study of limited scope, the following methodological limitations should be considered. This study involved a limited sample size of four female parents from the same school. Although the parent participants were from various provinces in South Africa, the parents shared similar experiences of their children with albinism, which may produce more homogenous results.

In terms of the data generation procedures, the study of limited scope relied on the knowledge generated by the parent participants during a single, three-hour focus group. The focus group comprised of PRA activities to generate the data that represented parental perspectives on the social justice needs of children with albinism. The focus group was conducted in English, which is not the participants' home language; this may have led to limitations when the participants described the social justice needs of children with albinism and relevant terminology in English.

Contrasts concerning the cultural backgrounds of the parent participants and myself may furthermore be considered as a possible constraint, due to the possibility of subjectivity. Moreover, my presence during the PRA activities may have affected participants' interactions. However, I remained mindful of my position as a qualitative researcher and kept a reflexive journal where I monitored my thoughts, experiences and perceptions.

5.6 RECOMMENDATIONS

In this section, I provide recommendations for future research, practice and training.

5.6.1 Recommendations for future research

Based on the findings of this study of limited scope, I recommend the following:

- The role of mothers of children with albinism being the primary advocates for children with albinism
- Comparative studies to explore the social justice needs of children with albinism globally

- Types of intervention required to address the psycho-social emotional challenges of children with albinism
- The role of family, communities and social networks in strengthening the social justice support for children with albinism.

5.6.2 Recommendations for practice

I recommend that the findings of this study be used to guide the development and implementation of strategies to support the social justice needs of children with albinism. Educational psychologists in practice can develop and implement Individualised Educational Plans (IEP) to address the specific needs of children with albinism in relation to visual impairment and psycho-social emotional challenges relating to their condition. In addition, by collaborating with teachers in schools, educational psychologists can tailor education plans to the unique needs of children with albinism, to ensure accessible learning opportunities. Moreover, teachers should be informed about ways to create inclusive and supportive learning environments. Educational psychologists can moreover offer parental guidance to parents of children with albinism by providing support and helping them navigate the social justice challenges faced by children with albinism.

5.6.3 Recommendations for training and development

The findings of this study of limited scope emphasise some areas in which parents of children with albinism can be supported in promoting health, well-being and access to education in mainstream schools for children with albinism. This includes the support of the government, teachers and healthcare professionals. I recommend that undergraduate students in professions, such as teaching, social work and educational psychology undergo training to ensure competency in terms of supporting parents and teachers to address the social justice needs of children with albinism in the contexts in which they specialise. More importantly, by highlighting the collaboration and support of parents, professionals may be trained to utilise the principles pointed out by parents in practice when planning interventions. In addition, teachers should receive appropriate training and development to equip them with the skills to support the needs of children with albinism through accommodations in the classroom. This includes, among others, being advocates for children with albinism to promote inclusivity in the educational context.

5.7 CONCLUDING REMARKS

In this study of limited scope, I explored parental perspectives on the social justice needs of children with albinism. The study forms part of the broader project and continuing research being conducted at the Centre for Visual Impairment Studies (CVIS) at the University of Pretoria. The findings of this study highlight parents' need for support in addressing the social justice needs of their children with albinism. It furthermore highlights the important role that parents play in supporting their children with albinism and advocating for their needs.

The study provides guidelines for addressing the social justice challenges of children with albinism, through the creation of government-inclusive policies that will recognise albinism as a disability in society and enable children with albinism to attend mainstream schools. A need was furthermore identified for social workers and healthcare professionals to inform parents about how they can assist their children with albinism to deal with their condition. In addition, the necessity of teacher training and development in supporting children with albinism in the educational context was identified.

Lastly, the need for parents, government, teachers and healthcare professionals to collaborate in advocating for the rights of children with albinism, as well as to increase knowledge and awareness of the condition of albinism to reduce stigmatisation and discrimination against children with albinism. The study additionally highlights that despite the lack of support received by parents of children with albinism from society and the limited knowledge regarding the condition of albinism, parents are still able and willing to support their children and advocate for their social justice needs.

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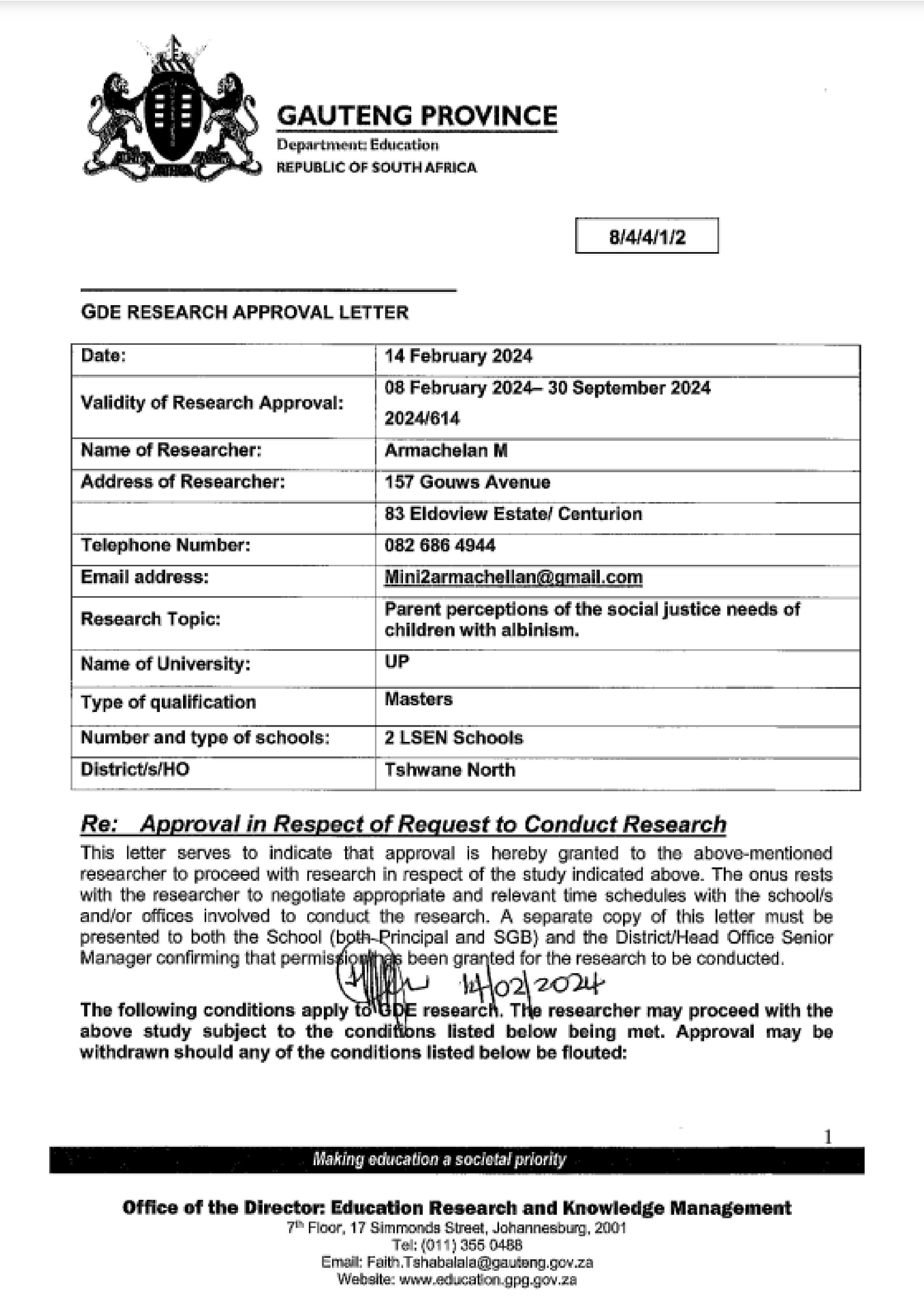
APPENDIX A: PERMISSION TO CONDUCT RESEARCH



GAUTENG PROVINCE
Department: Education
REPUBLIC OF SOUTH AFRICA

8/4/4/1/2

GDE RESEARCH APPROVAL LETTER

Date:	**14 February 2024**
Validity of Research Approval:	**08 February 2024– 30 September 2024** **2024/614**
Name of Researcher:	**Armachelan M**
Address of Researcher:	**157 Gouws Avenue**
	83 Eldoview Estate/ Centurion
Telephone Number:	**082 686 4944**
Email address:	**Mini2armachellan@gmail.com**
Research Topic:	**Parent perceptions of the social justice needs of children with albinism.**
Name of University:	**UP**
Type of qualification	**Masters**
Number and type of schools:	**2 LSEN Schools**
District/s/HO	**Tshwane North**

Re: Approval in Respect of Request to Conduct Research

This letter serves to indicate that approval is hereby granted to the above-mentioned researcher to proceed with research in respect of the study indicated above. The onus rests with the researcher to negotiate appropriate and relevant time schedules with the school/s and/or offices involved to conduct the research. A separate copy of this letter must be presented to both the School (both Principal and SGB) and the District/Head Office Senior Manager confirming that permission has been granted for the research to be conducted.

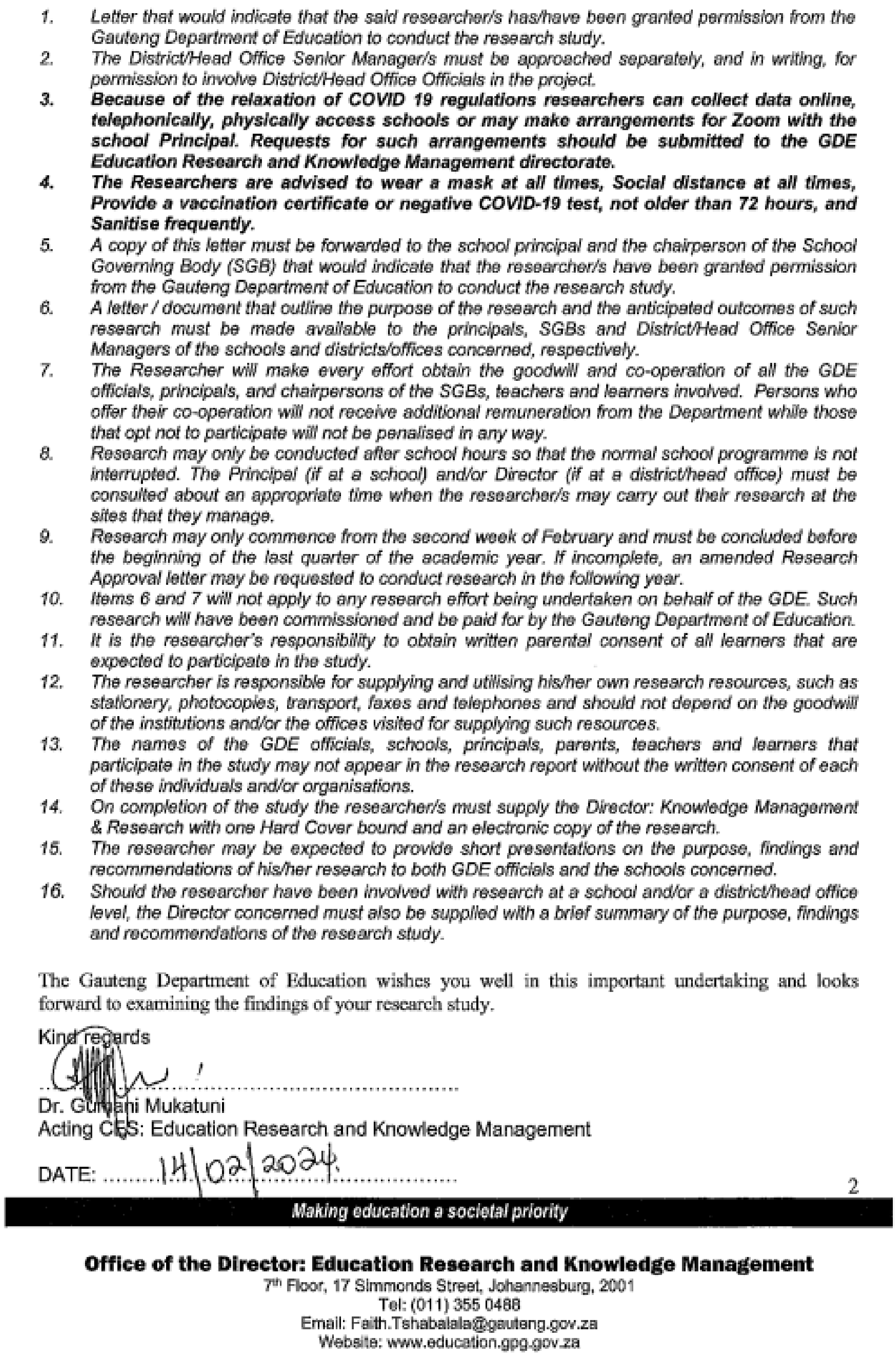
14/02/2024

The following conditions apply to GDE research. The researcher may proceed with the above study subject to the conditions listed below being met. Approval may be withdrawn should any of the conditions listed below be flouted:

1

Making education a societal priority

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
Tel: (011) 355 0488
Email: Faith.Tshabalala@gauteng.gov.za
Website: www.education.gpg.gov.za



1. *Letter that would indicate that the said researcher/s has/have been granted permission from the Gauteng Department of Education to conduct the research study.*
2. *The District/Head Office Senior Manager/s must be approached separately, and in writing, for permission to involve District/Head Office Officials in the project.*
3. ***Because of the relaxation of COVID 19 regulations researchers can collect data online, telephonically, physically access schools or may make arrangements for Zoom with the school Principal. Requests for such arrangements should be submitted to the GDE Education Research and Knowledge Management directorate.***
4. ***The Researchers are advised to wear a mask at all times, Social distance at all times, Provide a vaccination certificate or negative COVID-19 test, not older than 72 hours, and Sanitise frequently.***
5. *A copy of this letter must be forwarded to the school principal and the chairperson of the School Governing Body (SGB) that would indicate that the researcher/s have been granted permission from the Gauteng Department of Education to conduct the research study.*
6. *A letter / document that outline the purpose of the research and the anticipated outcomes of such research must be made available to the principals, SGBs and District/Head Office Senior Managers of the schools and districts/offices concerned, respectively.*
7. *The Researcher will make every effort obtain the goodwill and co-operation of all the GDE officials, principals, and chairpersons of the SGBs, teachers and learners involved. Persons who offer their co-operation will not receive additional remuneration from the Department while those that opt not to participate will not be penalised in any way.*
8. *Research may only be conducted after school hours so that the normal school programme is not interrupted. The Principal (if at a school) and/or Director (if at a district/head office) must be consulted about an appropriate time when the researcher/s may carry out their research at the sites that they manage.*
9. *Research may only commence from the second week of February and must be concluded before the beginning of the last quarter of the academic year. If incomplete, an amended Research Approval letter may be requested to conduct research in the following year.*
10. *Items 6 and 7 will not apply to any research effort being undertaken on behalf of the GDE. Such research will have been commissioned and be paid for by the Gauteng Department of Education.*
11. *It is the researcher's responsibility to obtain written parental consent of all learners that are expected to participate in the study.*
12. *The researcher is responsible for supplying and utilising his/her own research resources, such as stationery, photocopies, transport, faxes and telephones and should not depend on the goodwill of the institutions and/or the offices visited for supplying such resources.*
13. *The names of the GDE officials, schools, principals, parents, teachers and learners that participate in the study may not appear in the research report without the written consent of each of these individuals and/or organisations.*
14. *On completion of the study the researcher/s must supply the Director: Knowledge Management & Research with one Hard Cover bound and an electronic copy of the research.*
15. *The researcher may be expected to provide short presentations on the purpose, findings and recommendations of his/her research to both GDE officials and the schools concerned.*
16. *Should the researcher have been involved with research at a school and/or a district/head office level, the Director concerned must also be supplied with a brief summary of the purpose, findings and recommendations of the research study.*

The Gauteng Department of Education wishes you well in this important undertaking and looks forward to examining the findings of your research study.

Kind regards

....

Dr. Gumani Mukatuni
Acting CES: Education Research and Knowledge Management

DATE: ....14|02|2024.............................

Making education a societal priority

Office of the Director: Education Research and Knowledge Management
7th Floor, 17 Simmonds Street, Johannesburg, 2001
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APPENDIX B: INFORMED CONSENT (TEMPLATES)

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

Parental perspectives on the social justice needs of children with albinism.

Name of the Researcher:	Minishka Arnachellan
Faculty:	Education
Email:	minishkan@icloud.com
Name of Supervisor:	Dr Karien Botha
Supervisor Email:	karien.botha@up.ac.za
Institution:	University of Pretoria

PRINCIPAL AND THE SCHOOL GOVERNING BODY REQUEST FOR PERMISSION TO CONDUCT A RESEARCH STUDY

Dear Educator/Principal and the School Governing Body of ….

My name is Minishka Arnachellan, and I am a master’s student at the University of Pretoria. I am writing to you to humbly request your school’s involvement in the above-mentioned research study.

The purpose of the proposed study is to explore and describe parental perspectives on the social justice needs of children with albinism. I aim to explore the social justice challenges that children with albinism experience. Furthermore, I will describe the role of parents in relation to the social justice needs of children with albinism. In addition, I aim to provide recommendations regarding the strategies parents can utilise to promote the social justice needs of children with albinism.

Logistical information about the project

I would like to involve your school in this research study. The parents who are interested in participating in this study will share their own experiences of their children with albinism by stating their perspectives on the social justice needs of children with albinism. Parents will be required to participate in a workshop that includes brainstorming activities and a focus group. The workshop will be about 2 hours long, presented after hours at your school, this year. Throughout, the research team will be making field notes, taking photographs of the posters parents generate, making audio-recordings during the focus group and observing all activities. To introduce my research, I would like to request permission to visit your school after school hours or a time convenient to you and the parents. Should they be interested I shall make an arrangement with the school to meet with the parents on a parents' evening or meeting when they are required to visit the school. I will arrange a time before or after the meeting where I can commence with collecting my data. In this way we do not disrupt teaching time. Should any of the parents feel overwhelmed by the research activities, I will provide them with a telephone number where they can speak to an educational psychologist to support them.

Ensuring safety measures

Confidentiality will be ensured by using pseudonyms for all participants. All effort will be made to ensure that no harm will occur to the parents. They will be allowed to withdraw from participating in the study at any point/ time even without giving reasons should they wish to do so.

The results of the study will be utilised at the University of Pretoria for my dissertation, dissemination in journal articles and conference proceedings. The results and findings of the research could illuminate current practice in the development of support strategies for children with albinism by promoting their social justice needs.

I also would like to request your permission to use your data, confidentially and anonymously, for further research purposes, as the data sets are the intellectual property of the University of Pretoria and, where relevant, project funders. Further research may include secondary data analysis and using the data for educating purposes. The confidentiality and privacy applicable to this study will be binding on future research studies.

Should you agree to participate, please read the following:

- I consent that data from this study can be used for research purposes strengthening the social justice needs of children with albinism as well as for dissemination in research output as indicated in this letter.

I acknowledge that:

- I have been informed that participation is voluntary, and I am free to withdraw from the project at any time without explanation or prejudice and to withdraw any unprocessed data previously supplied.
- I have been informed that the confidentiality of the information collected will be safeguarded.
- My educational environment as well as I will be referred to by pseudonym or code name in the study and any publications arising from the research.

Researcher:
Minishka Arnachellan
University of Pretoria
Email address: minishkan@icloud.com
Cellphone number: 0826864944

Supervisor:

Dr Karien Botha

University of Pretoria

Email address: karien.botha@up.ac.za

Cellphone number: 082 074 9611

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

School Principal Consent Form

LETTER OF CONSENT:
PRINCIPAL CONSENT

VOLUNTARY PARTICIPATION IN THE RESEARCH PROJECT ENTITLED

"Parental perspectives on the social justice needs of children with albinism"

I, ______________________________________ (full name) hereby, in my capacity as a principal at …………………… grant permission to Minishka Arnachellan, a master's student from the University of Pretoria, to conduct the aforementioned research project at our school.

I declare that the aim, scope, and purpose of the research has been clearly outlined and the data collection methods were fully explained to me by the researcher. I have been assured that our schools' confidentiality and anonymity will be honoured throughout the study.

I give permission for the generated data to be used for further research purposes and understand that the data sets are the intellectual property of the University of Pretoria.

______________________________ ______________________________

Full name **Signature**

____

Date

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Education
Fakulteit Opvoedkunde
Lefapha la Thuto

Department of Educational Psychology

University of Pretoria

Dear Participant

I am an MEd student at the University of Pretoria and invite you to participate in my research study on parental perspectives on the social justice needs of children with albinism situated within the Centre for Visual Impairment Studies (CVIS). Before you decide to participate in this study, it is important that you understand why the research is being conducted and what your participation will involve. Please take the time to read through the following information and ask for any clarity you may need.

Purpose of the study:

The purpose of the proposed study is to explore and describe parental perspectives on the social justice needs of children with albinism. I aim to explore the social justice challenges that children with albinism experience. Furthermore, I will describe the role of parents in relation to the social justice needs of children with albinism. In addition, I aim to provide recommendations regarding the strategies parents can utilise to promote the social justice needs of children with albinism. The research conducted will contribute to the existing knowledge base at the Centre for Visual Impairment Studies (CVIS) at the University of Pretoria by addressing the current gap in the literature about parental perspectives on the social justice needs of children with albinism.

Research activities:

If you decide to participate, you will be required to participate in a workshop that includes brainstorming activities and a focus group. The workshop will be about 2 hours long, presented after hours at your school, this year. I shall arrange with the school to meet with you on a parents' evening or meeting when you are required to visit the school. I will arrange a time before or after the meeting when I can commence collecting my data. In this way, we do not disrupt teaching time. Should you feel overwhelmed by the research activities, I will provide you with a telephone number where you may speak to an educational psychologist for support.

Throughout, the research team will be making field notes, taking photographs of the posters and diagrams you generate, making audio-recordings during the focus group and observing all activities.

Potential benefits of participation:
By providing insight into your experiences and perspectives on the social justice needs of children with albinism, you will contribute to the knowledge base regarding visual impairment at the CVIS. The activities and discussions that you participate in may also be of value and provide you with ideas to implement in your daily lives.

Potential risks of participation:
No risks are foreseen, however, in the case of any such unfortunate event, it will be dealt with in a professional, ethical and confidential manner.

Confidentiality and anonymity:
All information obtained will be dealt with in a confidential way. You and your child's identity will be protected. With your consent, photographs will be taken of the posters and diagrams (spider diagrams and/or Venn diagrams) as a means of documentation. In addition, audio recordings of the dialogues during the workshop activities and focus group discussions will be taken and later transcribed. Your identity will be protected by using pseudonyms when reporting the data. No information or identities will be disclosed to anyone outside the research team. We would also like to request your permission to use the data, confidentially and anonymously, for further research purposes, as the data sets are the intellectual property of the University of Pretoria. Further research may include secondary data analysis using the data for educating purposes. The confidentiality and privacy applicable to this study will be binding on future research studies.

Compensation:
Since your participation in the study is voluntary, please note that you will not receive any monetary awards or awards in kind.

Voluntary participation:
Your participation in this study is voluntary. You can decide whether or not to take part in this study. If you decide to take part, you are still free to withdraw from the study at any time without any given reason.

If you are willing to participate in this study, please sign the attached letter as declaration of your consent, i.e. that you participate willingly in this study, that you understand that you may withdraw at any time and that you give permission for photographs and audio-recordings to be taken during the activities.

Yours sincerely

Ms Minishka Arnachellan	Ms CJ Botha
Researcher	Supervisor
0826864944	082 074 9611
minishkan@icloud.com	karien.botha@up.ac.za

Participant Consent

By signing this consent form, I confirm that I have read and understood the information and have had the opportunity to ask questions. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving a reason and without cost. I therefore voluntarily agree to take part in this study.

______________________________	______________________________
Full name of participant	**Participant's signature**

Current age of participant: ____

Age of child: ____

________________________	________________________	______________
Researcher's signature	**Witness' signature**	**Date**

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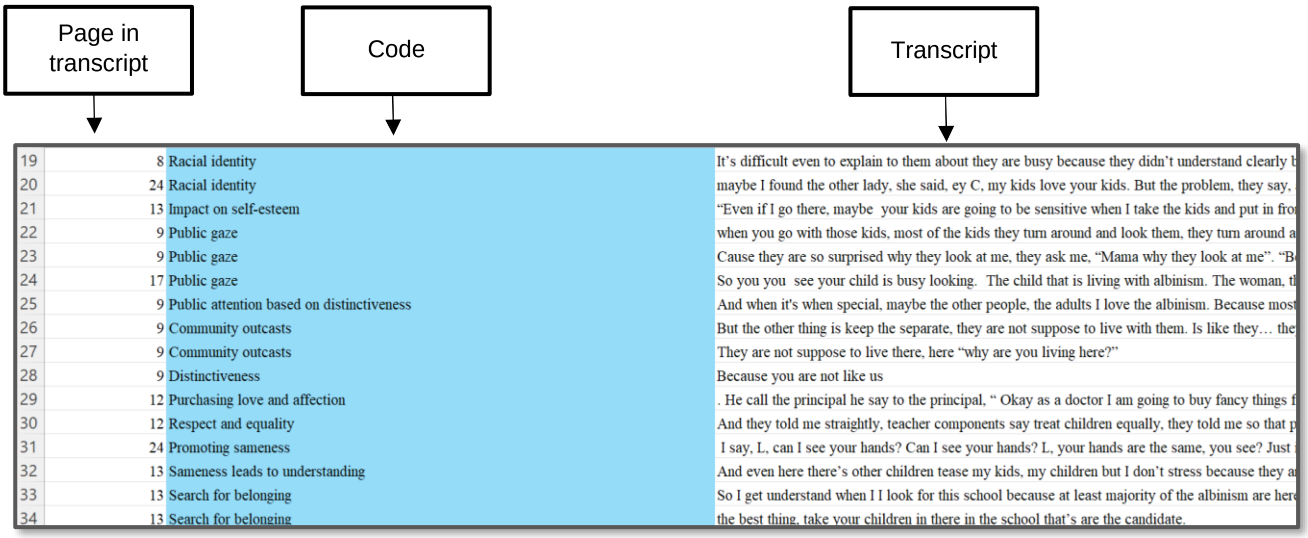
APPENDIX C: SAMPLE OF TRANSCRIBED AND CODED DATA

Participant 2: They call them with the names.	**Bullying and name calling**
Participant 1: It's so difficult to go and play with other children because the children, they, they tease them	**Bullying and name calling**
Participant 2: They don't like them	**Other children are not fond of children with albinism**
Participant 1: They tease them with names, like your skin is like a chicken. (baby cooing) Your skin is like a pork. Why your skin is like that? Why your eyes is like this? Because I remember other time when I'm in the church, there's other kids ask my kids why you don't like your mother because your mother is black you white, this means this is not your mother.	**Bullying and name calling** **Racial Identity**
Participant 1: When his at home, he ask me "Mama are you my real mama?" I say "agh wena what's wrong?" "I am your mom." He told me "No other kids they told me that me I'm white, you black which means you are not my mama." I say, "No I am your mother."	**Racial identity**
Participant 1: It's difficult even to explain to them about they are busy because they didn't understand clearly because when they see 90% in my church is the only albinism in my church. Is the only albinism. So, it's difficult to even explain to them why you are like this but the other twins say, "I am lucky because I am white." (laughs)	**Racial identity**
Researcher: So, both your twins have albinism?	
Participant 1: Yes	
Participant 4: Names, in brackets bad names.	
Participant 2: Yeah	
Participant 1: And ask them about their conditions	
Participant 1 : And another challenge is when you go with those kids, most of the kids they turn around and look them, they turn around and look them. And sometimes	

the other twins of mine is fine, the other one say “Ey wena just do like this…when they look like this.” (laughs)	**Public gaze**
Participant 1: Cause they are so surprised why they look at me, they ask me, “Mama why they look at me?”. “Because you are beautiful.” That is why they look at you well. And you are beautiful. “But Mama all the people, they just turn around and look at me.”	**Public gaze**
And when it's when special, maybe the other people, the adults I love the albinism. Because most of the time when we go and maybe to the mall, “Can we take a photo with them…can I take a photo with them?” They are happy when they find people who want to take a photo with them. They are happy.	**Public attention based on distinctiveness**
Participant 2: But the other thing is keep them separate… they are not supposed to live with them. Is like they… they have a place to go and live there the way they are talking. Participant 1: Yeah	**Community outcasts**
Participant 2: They are not suppose to live there, here “why are you living here?”	**Community outcasts**
Participant 1: Because you are not like us Participant 2: Like us … hmm.	**Distinctiveness**

Sample of Coded Data Exported to Microsoft Excel



19	8	Racial identity	It’s difficult even to explain to them about they are busy because they didn’t understand clearly
20	24	Racial identity	maybe I found the other lady, she said, ey C, my kids love your kids. But the problem, they say,
21	13	Impact on self-esteem	“Even if I go there, maybe your kids are going to be sensitive when I take the kids and put in fro
22	9	Public gaze	when you go with those kids, most of the kids they turn around and look them, they turn around
23	9	Public gaze	Cause they are so surprised why they look at me, they ask me, “Mama why they look at me”. “
24	17	Public gaze	So you you see your child is busy looking. The child that is living with albinism. The woman,
25	9	Public attention based on distinctiveness	And when it's when special, maybe the other people, the adults I love the albinism. Because most
26	9	Community outcasts	But the other thing is keep the separate, they are not suppose to live with them. Is like they… the
27	9	Community outcasts	They are not suppose to live there, here “why are you living here?”
28	9	Distinctiveness	Because you are not like us
29	12	Purchasing love and affection	. He call the principal he say to the principal, “ Okay as a doctor I am going to buy fancy things
30	12	Respect and equality	And they told me straightly, teacher components say treat children equally, they told me so that
31	24	Promoting sameness	I say, L, can I see your hands? Can I see your hands? L, your hands are the same, you see? Just
32	13	Sameness leads to understanding	And even here there’s other children tease my kids, my children but I don’t stress because they
33	13	Search for belonging	So I get understand when I I look for this school because at least majority of the albinism are here
34	13	Search for belonging	the best thing, take your children in there in the school that’s are the candidate.

CODES EXTRACTED FROM MICROSOFT EXCEL (IN ALPHABETICAL ORDER)

1.	Acceptance of children with albinism in all government schools
2.	Acceptance of children with albinism in any school in South Africa
3.	Beliefs and superstitions
4.	Bullying and name-calling
5.	Children with albinism cannot be left alone
6.	Children with albinism cannot be left with anyone else besides their parents
7.	Children with albinism should be treated fairly by teachers
8.	Community outcasts
9.	Dietary requirements
10.	Discrimination in mainstream schools
11.	Distinctiveness
12.	Educating children with albinism about their condition
13.	Employment of social workers by the government
14.	Encouraging children with albinism
15.	Expenses incurred by parents
16.	Failure to recognise albinism as a disability
17.	Fear of safety
18.	Fear of traditional healers
19.	Government housing and security
20.	Government policies allowing children with albinism to go to any school
21.	Government strategies to educate parents of children with albinism

22.	Health challenges related to the condition of albinism
23.	Knowledge of harm against children with albinism
24.	Lack of acknowledgement from the government
25.	Lack of knowledge surrounding albinism
26.	Lack of financial support
27.	Lack of financial support from the government
28.	Lack of support from mainstream schools
29.	Nutrition
30.	Other children are not fond of children with albinism
31.	Parents need to be overprotective
32.	Parental support
33.	People are afraid of children with albinism
34.	People are afraid to stay with children with albinism
35.	Prayers and devotion
36.	Promoting sameness
37.	Public gaze
38.	Public attention based on distinctiveness
39.	Purchasing love and affection
40.	Racial identity
41.	Recognition and acceptance at universities
42.	Recognition and acceptance at the workplace
43.	Removal from mainstream schools

44.	Respect and equality
45.	Sameness leads to understanding
46.	Search for belonging
47.	Skincare and protection
48.	Training of teachers in response to the condition

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APPENDIX D: FIELD NOTES

Date	26 July 2024
Event	Research study- focus group
Researchers	Minishka Arnachellan, Nadia Bode
Research Site	Special needs school
Number of participants	Four
Length of the session	11:00-14:00

• We were greeted on arrival by the deputy principal who referred us to an educator at the school. The educator escorted us to the conference room where we could set up and prepare for the session.	
• Participants began arriving soon after 11:00, however, we waited until 11:30 for the last participant to arrive. It was mentioned that the participants travel from afar and most of their children stay at the school hostel. Every Friday, parents are required to fetch their children from the hostel and return them to the hostel on Monday, after the weekend. It was therefore convenient to invite the participants to engage in the session on a Friday.	**Potential transport challenges (loss of session time)**
• One of the participants attended the session with their baby, which had an impact on the participant’s involvement in the focus group.	**Potential challenges arranging childcare (limits attendance during the session)**
• Since there were only four participants, only one focus group could be formed.	
• All the participants were female.	**Limits generalisability**
• Even though the participants stated that English was not their first language, they tried their best to communicate in English while still using some words in their mother language to describe their	**Possible language barriers and literacy barriers (limits involvement)**

experiences. However, it was observed that one of the participants only spoke a few words due to the language barrier. Furthermore, only one participant was able to write in English on the posters.	
• The group collaborated well; however, some participants spoke more than others and it was mentioned at the end by one participant that she did not get to share the daily challenges she faced as a parent of a child with albinism.	**Limits to involvement and time constraints**
• It was noted that discussions regarding the daily challenges faced by parents of children with albinism outweighed the resources that support children with albinism. The participants were, therefore, able to discuss the challenges they faced with ease; however, they took time to respond to questions regarding support resources.	**Numerous challenges experienced by parents of children with albinism and lack of support**
• The debrief session at the end was brief as participants did not add to their statements when discussing the content they had written on the posters.	**Limited data**
• At the end of the session, the participants stated that they enjoyed it, and it was very helpful. They mentioned that they were able to learn from each other and it was good to know that some of them experienced similar challenges.	**Positive feedback**

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APPENDIX E: REFLECTIVE JOURNAL

Reflexive Journal **July 2024**

All contact made with the parent participants was done through the school and with assistance from the social worker based at the school. I therefore had no contact with the participants prior to the research study. However, I previously participated as a fieldworker in another research study a month before the data generation of my research study. I, therefore, believe that I had some expectations in terms of how participants responded and did not consider the impact of the language barrier that may limit participants' responses. The special needs school caters for visually impaired learners and is therefore a main resource centre for children with albinism in Pretoria, based on this I expected a large number of parent participants to attend the research study. However, only four participants were able to attend.

At the beginning of the research study, it was evident that the parent participants did not know what to expect from the session. When the first poster and research question was presented to the participants, initially it took the participants some time to determine how they would respond to the research question. However, after ensuring the participants that spelling and grammar do not matter and that they can express themselves in any way they wish, the participants were more comfortable and able to communicate their thoughts effectively. I wonder if participants did not have to write their responses down and perhaps another method of allowing them to record their responses was utilised, each participant would be able to provide more in-depth responses. It was observed that one of the participants did not share too much and only expressed a few words due to the language barrier. Furthermore, recording the responses of participants took time as the participant selected for writing on the posters wrote slowly to ensure that she captured responses accurately.

The parent participants stated that they spend time with their children three days a week and only in the school holidays do they see them more often due to their children residing at the school hostel as most of the participants stay in other provinces. I, therefore, wondered about the attachment and parent-child bond that exists between the participants and their children due to the distance and separation from their parents after every weekend. However, the parent participants shared that they tend to spoil their children and shower them with love when they see them.

Initially, I expected that parents would mostly discuss the social discrimination faced by their children with albinism, however, I experienced that parents were equally concerned about the medical care, education in mainstream schools and the lack of support received by the government. It was evident that parents require tremendous support for their children with albinism. The value of the face-to-face discussion led to insightful knowledge of the challenges that are faced by children with albinism and their support needs. I found that the parents were able to confirm most of the challenges I have read in research which made their experiences more valuable.

I found difficulty in probing and asking questions without leading the participants. I therefore had to reassess ways of approaching the discussions ethically and sensitively. I, furthermore, had to be mindful of the emotional responses I provided to participants as this led to participants emphasising sensitive experiences. At the end of the session, participants appeared tired. I needed to be aware of time challenges and perhaps should have provided the participants with short comfort breaks in between.

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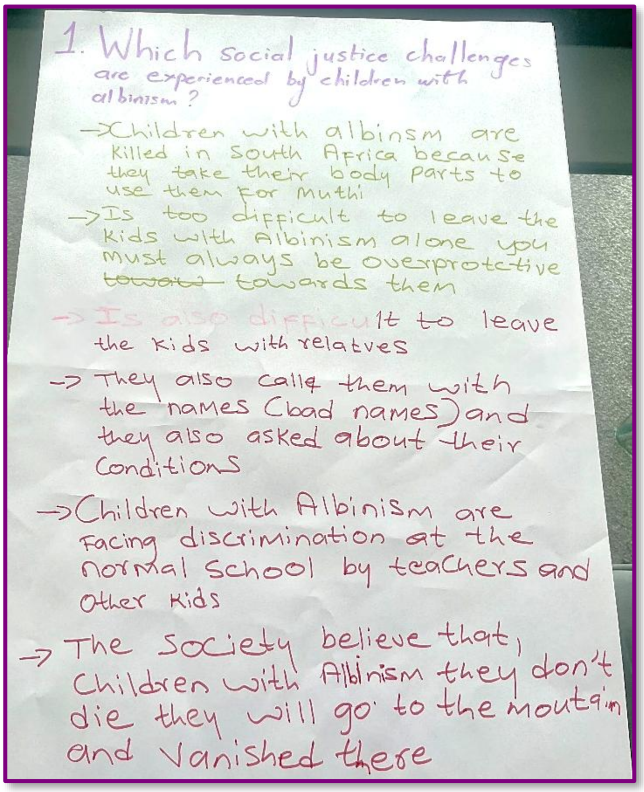
APPENDIX F: ORGANISING CODES INTO THEMES

POSTER 1, JULY 2024



1. Which social justice challenges are experienced by children with albinism?

→ Children with albinsm are Killed in South Africa because they take their body parts to use them for muthi

→ Is too difficult to leave the kids with Albinism alone you must always be overprotective ~~toward~~ towards them

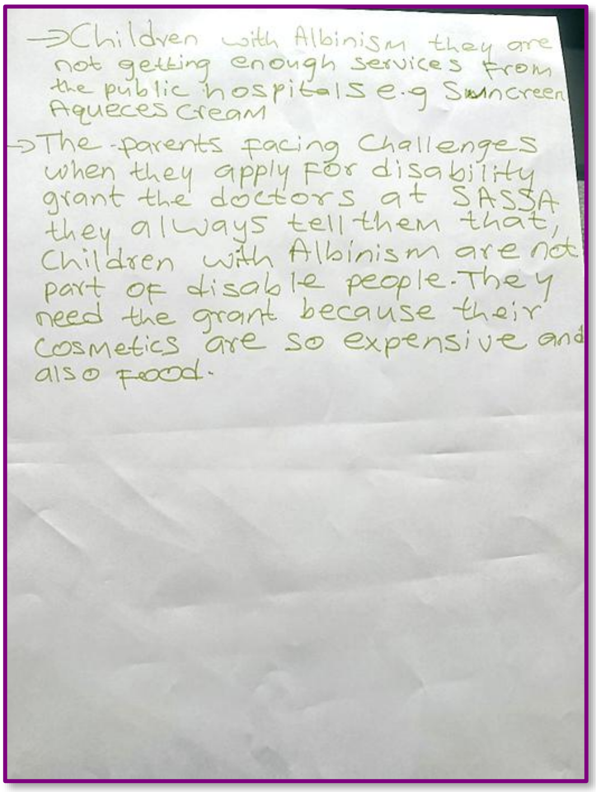
→ Is also difficult to leave the kids with relatves

→ They also calle them with the names (bad names) and they also asked about their conditions

→ Children with Albinism are Facing discrimination at the normal School by teachers and other kids

→ The Society believe that, Children with Albinism they don't die they will go to the moutain and Vanished there

Photograph: challenges identified by parents of children with albinism

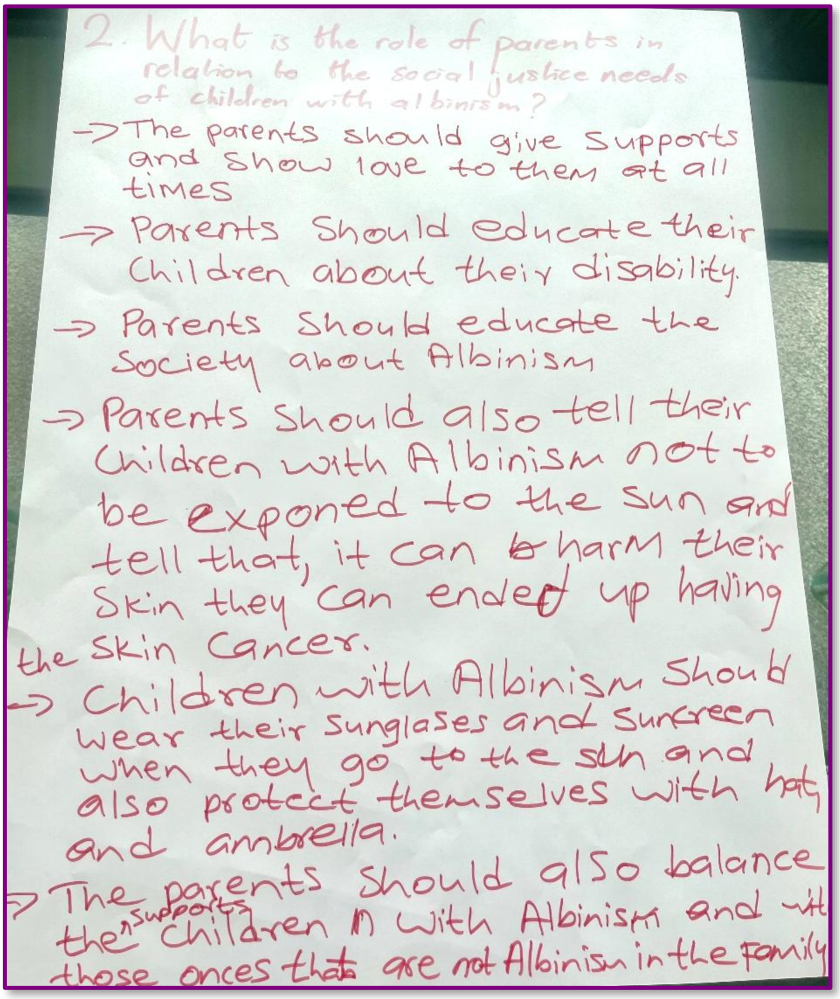


→ Children with Albinism they are not getting enough services from the public hospitals e.g Suncreen Aqueces cream

→ The parents facing Challenges when they apply for disability grant the doctors at SASSA they always tell them that, Children with Albinism are not part of disable people. They need the grant because their cosmetics are so expensive and also food.

Photograph: challenges identified by parents of children with albinism

POSTER 2, JULY 2024



2. What is the role of parents in relation to the social justice needs of children with albinism?

-> The parents should give supports and show love to them at all times

-> Parents Should educate their Children about their disability.

-> Parents Should educate the Society about Albinism

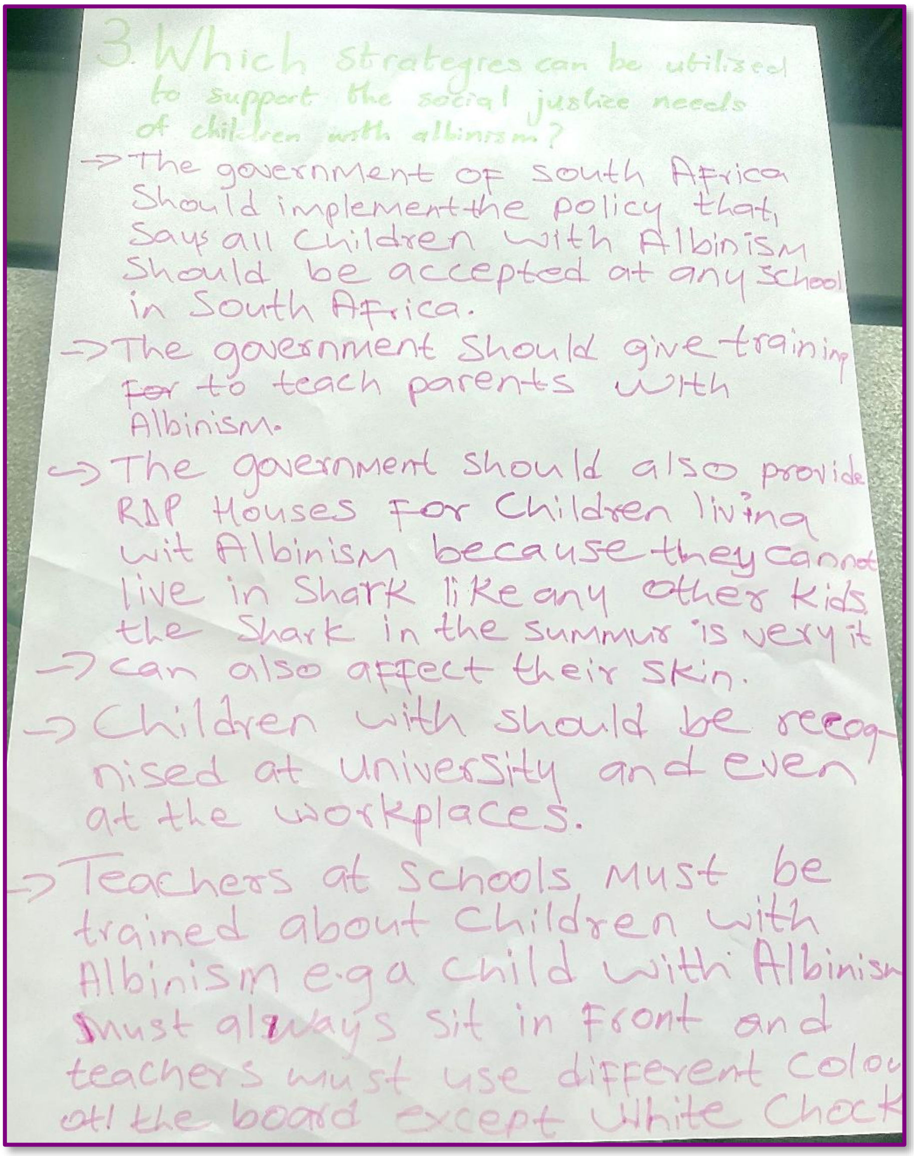
-> Parents Should also tell their Children with Albinism not to be exponed to the sun and tell that, it can ~~b~~ harM their Skin they can ended up having the Skin Cancer.

-> Children with Albinism Shoud wear their Sunglases and Sunscreen when they go to the sun and also protect themselves with hat, and ambrella.

-> The parents Should also balance the supports Children ~~n~~ with Albinism and wit those onces that are not Albinism in the Family

Photograph: parents role in relation to the social justice needs of children with albinism

POSTER 3, JULY 2024



3. Which strategies can be utilised
to support the social justice needs
of children with albinism?

-> The government of south Africa
Should implement the policy that,
Says all Children with Albinism
Should be accepted at any School
in South Africa.

-> The government Should give training
~~For~~ to teach parents with
Albinism.

-> The government should also provide
RDP Houses for Children living
wit Albinism because they cannot
live in Shark like any other kids
the Shark in the summur is very it
-> can also affect their Skin.

-> Children with should be recog-
nised at university and even
at the workplaces.

-> Teachers at Schools must be
trained about Children with
Albinism e.g a child with Albinism
must always sit in Front and
teachers must use different colou
on the board except White Chock

Photograph: strategies identified by parents to support the social justice needs of children with albinism

PARTICIPANTS, JULY 2024

Photograph: parent participants, participating in PRA activities.

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