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***TITLE:***  
***AN EXPLORATION OF  
ALBINO IDENTITY  
AMONGST GROUPS OF  
TEENAGED GIRLS AT A  
SPECIAL SCHOOL IN  
KWAZULU-NATAL,  
SOUTH AFRICA.***

By

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*Submitted in partial fulfillment of the requirements for the  
degree Masters of Philosophy in Group Therapy in the School  
of Occupational Therapy at the University of KwaZulu-Natal  
(Westville campus).*

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### **Declaration**

1. I, Farhana Vally, hereby declare that this dissertation and research is my own original work unless where otherwise indicated. This dissertation has not been submitted for any degree or examination at any other university.
2. This dissertation does not contain another persons' writing, unless where it has been specifically acknowledged. Sources have been used in this dissertation according to the following:
  - a. Where their words has been paraphrased, information has been attributed to them through referencing.
  - b. The use of exact wording has been put in quotation marks and referenced illustrating that it is a quote.

Signed:

  
\_\_\_\_\_  
Farhana Vally

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## **ABSTRACT**

A qualitative study probing Albino Identity amongst groups of teenaged girls at a special school in order to find out if a group identity based in Albinism exists. An exploratory research design allowed the researcher to explore the worldview from the participant's perspective. The method of investigation used three focus groups of four participants each to explore the psycho-social constructs that defined the shared reality of the participants as a group because of medical condition. Personal accounts from the participants facilitated the exploration of their perception through homogenous focus groups.

This study had four objectives. The first objective was to examine how the social identity shapes the personal identity of the participants with Albinism. The second objective was to explore and identify common social experiences that the participants shared which have meaning for them in order to better understand their personal reality as a group. The third objective was to understand how social constructs contribute to defining the personal reality of the participants. The fourth objective of this study was to explore the psycho-social reality of Albino Identity as a shared group identity.

The data yielded from the three focus groups was analysed using Thematic Analysis. Themes that emerged from the focus group were grouped into three broad heading namely Differentiation Based On a Lack Of Pigmentation, Treated Differently Because of Colour and Albinism Changes Social Interaction.

The study's findings show that the social identity changes the personal identity in the same way. The participants share the same experiences with the social identity due to the lack of pigmentation. The participant's personal identity is altered through social interaction with the group mind. Social interaction with social constructs such as family and peers were more meaningful to the participants than with strangers.

Albino Group Identity does exist and has value for the participants because it creates a sense of belonging and community for the participants outside of their family. Participants also reported being more comfortable around large numbers of Albinos because there is an absence of threat and hostility, giving the participants more security and acceptance. Members of the identity group based in Albinism regards the lack of pigmentation as a norm. This study has identified several group norms observed by its group members of Albino Group Identity. Safety concerns regarding the sun is a group norm along with dressing for the sun. Group members also reconstitute their behaviour to accommodate the social identity. The group strive for normality is the antithesis to the myths based in the collective unconscious. Albino Group Identity also demands the resolution of an identity crisis that is based in the colour that is created by Albinism.

The findings of this study allows for practical adaptation of group therapy with learners with Albinism who present with maladaptive behaviour patterns. Future research in the area of group identity amongst persons with Albinism is recommended.

## **ABBREVIATIONS AND TERMINOLOGY**

UKZN- University of KwaZulu-Natal

BRECS- Board of Research Ethics Committee

Zulu- An ethnic group of Africans who speak the African language Zulu. Members of the Zulu tribe are also called a Zulu.

Eshowa-A derogatory swear word in the Zulu language

Muti-Traditional African herbal medicine

Mlungu- A Caucasian

Sangomas -(plural)- A traditional healer who makes muti to cure people

**Adolescent:** The final stage of childhood (Erik H Erikson, 1974). Adolescence is a stage of development that precedes adulthood, starting at the age of 12 until the age of 18 years.

**Albinism:** A medical condition resulting from a genetic abnormality. A reduction in the production of melanin results in a lack of pigmentation in the hair, skin and eyes. The lack of pigmentation changes the colour of the person with Albinism. The skin appears white and translucent. The eyes appear blue or green. The hair can be blond or ginger.

**Albino:** A person who has the medical condition of Albinism. Some people have taken offense to the term Albino but this term is used in this study because the participants used this term to describe themselves. The literature that informs this study also used the term Albino to describe a person with Albinism.

**Group Identity:** That commonality amongst different people based on a similar life experience. It is a specific collective identity that depends on the social and personal identity. The social identity is based in the collective unconscious and comprises traditional beliefs and archetypes. The personal identity is based on the individuals life experience and interaction with the social identity.

**Albino Identity:** A personal identity that is shaped primarily by the medical condition of Albinism. Albino Identity was first introduced to research by Ngaire Blakenberg in 2000 where she specifically outlined criteria that delineates Albino Identity as a separate and distinct identity.

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## **CHAPTER ONE: OVERVIEW**

### **1.1 INTRODUCTION**

Albino Identity is a term introduced into research by Ngaire Blakenberg (2000). She used this term to describe an identity group whose self-concept is defined by the medical condition of Albinism. Albinism is a rare genetic condition. KwaZulu-Natal has a special school that has a large number of learners with Albinism. The learners range in age from 7 to 21 years old. Most of the high school learners are teenagers. Adolescence are in the final stage of identity development (Erikson, 1974). It is unknown if Albino Identity exists as a shared identity amongst teenaged girls. This study intends to explore the Albino Identity amongst a group of teenaged girls in order to understand if Albino Identity exists as a group identity.

This chapter will outline the study including the aim, rationale and objectives. The objectives will outline those steps that will be taken to achieve the aim.

### **1.2 BACKGROUND**

“I have made you into nations and tribes so that you may know one another”

The Holy Qur'an (49:13)

This quote is cited from the Holy Quran that was revealed in 632AD, indicating the importance of groups as an integral part of society through which we learn about others and ourselves. Understanding another tribe, nation or in this case group, we can also know the members of our own group and learn more about ourselves through the observation of others with whom we share an identity. “...to know one another...” reiterates that identity must be discovered, explored, unpacked and understood. Identity is a tangible entity that can be dissected, analysed and documented (Woodward, 2002).

A group, by definition, constitutes social relationships with others (Rioch, 2009). A group exists independently of geographical location. It is a sense of social belonging and social identification (Young, 2003). Thus social

identification with others exists within the individual because it is part of a group identity. This study will be exploring the group identity amongst learners attending a special school in KwaZulu-Natal to understand if being born with Albinism contributes to a social identification with others who have Albinism despite geographical isolation from other Albinos.

“The identity story is one that has been told around different relationships...” (Woodward, 2002, p.1). Individuals who share social experiences, integrate it into their identity through similar relationships. Goffman (1975) refers to the social experiences and relationships as separate identities within any individual. He called it social identity and personal identity (Goffman, 1975). “Social and personal identity are part, first of all, of the other persons’ concerns (or perceptions) and definitions regarding the individual whose identity is in question...” (Goffman, 1975, p.129). Social identity exists independently of any person. McDougall (1921) referred to nationalism as an example of a social identity which exists in the group mind and alters personal identity of individuals.

Personal identity is the individual’s experience with the opinion that others have of herself. Through this interaction with the social identity the individual attaches meaning and value to the experience which defines personal identity (Goffman, 1975). Social identification with others is sharing a personal identity that has arisen from social interactions. Together the shared personal identity and social identity constitutes a group identity that is based in an unspoken understanding and offers a sense of social belonging (Goffman, 1975).

A researcher, Ngaire Blakenberg, interviewed several people with Albinism and concluded that Albino Identity is recognisable as a separate identity and able to be qualified. She titled her research “That Rare and Random tribe: Albino Identity in South Africa” (Blakenberg, 2000, pp.1). Blakenberg (2000) outlined how the personal identity of those with Albinism had been changed due to the medical condition.



Albinism is an easily identified disorder amongst well pigmented populations like African Zulu's in KwaZulu-Natal. It presents with a lack of pigmentation of the skin, hair and eye colour. This results in a pale, translucent "white" skin, blond hair and blue/green eyes (King & Summers, 1988). "Their appearance is...strikingly different from their darkly pigmented peers, resulting in a range of social...problems" (Gaigher et al., 2002, pp.4). Albinism is associated with multiple eye problems that range in severity from mild photosensitivity and can include disabling blindness, severe near sightedness, nystagmus and strabismus (King & Summers, 1988). People with Albinism have normal intellectual functioning and academic ability. Many with severe eye problems attend a special needs school in KwaZulu-Natal.

The researcher worked at a special needs school as an Occupational Therapist. She noticed the strong, negative reaction of others to the learners with Albinism. A young 9 year old child was overheard reacting with reservation: "Are they Zulu or are they white?" This sentiment is echoed in Blakenberg's (2000) published article where she describes how people reacted to her. "What they didn't say with their voice, they said with their eyes, following me always and wondering who this wild creature was among them, this wild whiteness in an ocean of black" (Blakenberg, 2000, pp. 7). She talks explicitly of an "Albino Identity" which she describes as an identity that is "...the Other of African identity, and the Other in Western discourse" (Blakenberg, 2000, pp.8). A perusal of this article sparked an interest in Albino Identity for the Occupational Therapist because she had never heard the term before. The Occupational Therapist wondered if Albino Identity could exist as a group identity.

Blakenberg's (2000) interviews revealed that the visual impairment associated with Albinism was not a concern but the colour of their skin presented with difficulties. It is interesting that Blakenberg's (2000) description of Albino Identity is without disability identity despite the eye problems associated with Albinism. Blakenberg (2000) makes no mention of the impact of this disability on the development of self-identification and Albino Identity. Her focus is entirely on Albino Identity as a social displacement.

The way that members of different social groups react to the physical appearance of those with Albinism can be alienating for the Albino. This continuous reaction from the broader social group will, inevitably, affect the mind, perspective and conceptualization of the self of a person living with Albinism because "...social interaction precedes the organisation of the inner self" (Knauss, 2007, p.162). Therefore, those with Albinism can be displaced from the majority group identity through social interaction.

Social interaction is described as "the organiser" of the psyche through a process of internalisation affecting the individual's social unconscious, sense of belonging, inner dialogue, process of communication, ego strength and adaptability (Dalal, 2002). This, inevitably, defines the personal reality of the individual. In an autobiography, Mongezi Ngidi (2005) referred to his Albinism as a condition that is "...the most important purpose and meaning to my life..." (p.3). This quote speaks of Ngidi (2005) perception of his Albinism. It can be inferred that having this medical condition has meaning and value in shaping his life and sense of self. His Albinism is the primary foundation of his identity because it defines who he is and gives him purpose. These sentiments were supported in a study by Gaigher et al. (2002) who found that "both as a social construct and a social status, Albinism affects all aspects of individual lives" (pp.10).

This study seeks to understand those relationships that comprise the common story amongst a group of teenage girls with Albinism. Understanding those relationships that have meaning to female Albino teenagers will allow insights into those aspects that shape their identity and cultivate their personal story. This study aims to explore the psycho-social constructs that may have influenced the identity development of teenaged girls with Albinism in order to find out if Albino Identity exists as a group identity.

### **1.3 PROBLEM STATEMENT**

The researcher was not able to find literature on the group identity of teenaged girls with Albinism in South Africa nor the prevalence of Albinism in

KwaZulu-Natal. Thus a gap in the research knowledge base has been identified by the researcher. This study may contribute new knowledge to the research base by investigating if Albino Identity exists as a group identity. Understanding the shared social and personal identity amongst the teenagers will establish which psycho-social constructs defines Albino Group Identity.

The researcher works with the participants at the school in her capacity as an Occupational Therapist. As the Occupational Therapist in the school, the researcher notices that often teenagers with Albinism present with maladapted responses and can have difficulty with authority. This study could offer possible recommendations for group therapists working with maladapted teenagers with Albinism. It could facilitate an adaptation of group therapy to improve the quality of life experiences through more effective service delivery. Findings from this study could lead to an adaptation of therapy via a betterment of group structure to enhance therapeutic group dynamics and group function. This is especially true in instances when improved social participation is needed from teenagers that are socially isolated or socially maladapted.

#### **1.4 RESEARCH QUESTION**

How do groups of adolescent girls with Albinism at a special needs school experience their identity?

#### **1.5 AIMS AND OBJECTIVES**

The aim of this study is to explore Albino Identity amongst groups of teenaged girls at a special needs school in KwaZulu-Natal to find out if Albino Identity exists as a group identity.

The study had the following objectives:

1. To explore how the social identity shapes the personal identity of participants with Albinism.
2. To explore and identify common social experiences that the participants share which have meaning for them, to better understand their shared personal reality

3. To explore the role that social constructs play in shaping the personal identity of participants living with Albinism.
4. To explore the psycho-social reality of Albino Identity as a shared group identity.

## **1.6 DELIMITATIONS**

- This study has chosen to study teenaged girls who have the medical condition of Albinism.
- Female candidates were chosen for this study because there were a larger number of female learners available for the study.
- The researcher has focused this study on group identity because no research on group identity amongst teenaged girls with Albinism was found.
- This study takes a psycho-social approach to the exclusion of disability identity, black consciousness and ethnic identity. This is a deliberate focus of the researcher with the intention of focusing on the humanity of the participant's lives and identity.
- Time constraints were imposed on the researcher to conduct the focus groups by the school authority. The senior management allowed the study on condition that the disruption on the academic programme be limited. This was accommodated by the researcher who conducted the research during pastoral care of learners.

## **1.7 SUMMARY OF CHAPTER ONE**

This study seeks to understand the shared experiences of teenaged girls with Albinism in order to understand if a group identity exists amongst the participants. The participant's perception of their experiences with others defines their reality. This study will explore the meaning and value that the participants add to these events and the extent that it shapes their world view and personal identity. A group identity can be recognised if there are common features amongst the participants that is based in Albinism.

## **CHAPTER 2: LITERATURE REVIEW**

### **2.1 INTRODUCTION**

This literature review will explain the chosen framework of this study and define key concepts pertinent to this study. These concepts include an ontological understanding of identity, group identity, Albinism and Albino Identity. The intention of this literature review is to provide a conceptual foundation for the research to explore the possibility that Albino Identity exists as a group identity amongst teenage girls with Albinism. Conceptual foundation underpin important aspects considered in research, offering the researcher direction and method. This study will be examining the life experiences of female participants. Therefore, the researcher has chosen to use feminine pronouns as a matter of efficiency which in no way is indicative of gender bias. The use of 'she' or 'her' in this literature review is merely for the ease of language usage but in no way excludes any gender group.

The researcher has chosen a psycho-social group framework because it proffers a variety of models to understand the group identity amongst teenage girls. "Models are cognitive maps, representations, schemes or scripts that an individual has about herself (as a unique bodily and psychic entity) and her environment" (Marone, 1998, p.71). These models are intrinsic and pertain to internal self-concepts within the individual. They arise within the individual through interaction with others (Pietromonaco & Barret, 2000). Blakenberg (2000) complements these frameworks by offering a model outlining Albino Identity that delineates the identity of those with Albinism.

### **2.2 PSYCHO-SOCIAL GROUP FRAMEWORK**

The psycho-social group framework is a necessary foundation to explore group identity. Several disparate psychoanalytic theories are incorporated to understand identity. "...psychoanalytic theories play a significant part in the investigation of identity at many different points in the story..." (Woodward, 2002, p.16). Psychoanalytic theories offer this study an understanding of the participant's perceptions that reflect their personal identity and how this has

been influenced by the social identity. The theoretical framework will validate the existence of an authentic group identity that is configured from the personal identity. Groups, however, cannot be explored without the social aspects of relationships between humans and the dynamic exchanges between minds. "Modern psychodynamics is a form of social psychology. It suggests a model in which the distinction between the individual and others begin to dissolve" (Wetherell, 1996, p.111). The diffused boundary between individuals in groups is of particular interest in this study.

The psycho-social group framework encompasses Goffman's Theory of Spoilt Identity, McDougall theory of group mind together with Le Bon's theory of crowd psychology and Foulkes' group theory. The application of these theories are under the guidance of Blakenberg's model of Albino Identity as a personal identity framework for the participants which will be understood in psychodynamic terms using theories from Freud, Jung and Erikson.

Goffman's (1975) theory of Spoilt Identity says that the social identity of society creates the personal identity of what he termed a stigmatised person. He outlines how social interaction with the social identity informs the disabled person of her disability. This theory explains that all stigmatised people are stigmatised by society in the same way. Group identity of stigmatised people as a minority group is overlooked.

McDougall (1921) presents the theory of the group mind amongst people who are part of a group using patriotism as his primary reference. His theory introduces the group mind as the source of a common value system in society. The group mind governs behaviour of individuals in broader society (McDougall, 1921). McDougall's (1921) focus is on the group mind but overlooks the crowd as a reactive group subjected to situational circumstances. Le Bon's (1896) investigation of crowd psychology resolves that crowds react instinctively and without cortical reasoning. Le Bon (1896) attributes this behaviour to the group mind. Foulkes (as cited in Dalal, 2002) attributes behaviour to the same method of socialization. He believed that it's the social aspects of group interaction that is the primary organiser of the

individual's psyche. These psycho-social theories comprise the framework of this study but none relate specifically to Albinism.

The model of Albino Identity is specific to people with Albinism. Primarily, participants are seen as teenagers with a medical condition irrespective of cultural background. This study will consider how their identity emerges through the interaction with others (Pietromonaco and Barret, 2000). In other words, this study will be exploring how the personal identity is shaped by the social identity through social interaction that is altered by Albinism. The alteration of identity due to Albinism creates Albino Identity through social interaction with society, family and groups like at mainstream school or the special school. The influence of these groups in shaping Albino Identity will be explored in terms of psychodynamic theories like Freud and Jung. Jung's theories of myths and archetypes will be a particular focus of this literature review.

Understanding key concepts in research is fundamental for the theoretical framework. This section will be defining the concept of identity, group identity, Albinism and Albino Identity. Identity will include a review of the literature and theory that explains identity and identity development with a focus on teenage identity development. Group identity will elaborate on the foundation of identity. Albinism will be defined in accordance to the many facets that Albinism presents. A medical definition of Albinism will be offered but also a personal definition of what is Albinism to the person living with the condition. Related research of the psycho-social constructs that surrounds Albinism will be reviewed. The focus of Albino Identity will include a review of the literature pertaining to Albino Identity and an examination of psycho-social constructs that contribute to Albino Identity.

## **2.3 IDENTITY**

Erikson (1974) explained identity simply as a concept that a person has of herself. Woodward (2000) elaborated on Erikson's (1974) definition and described identity as the cognitive concept that answers the question "who am I", offering a probing definition of identity. Identity, simply defined within "...the

common sense meaning of the term – the emphasis on sameness over time or across persons” (Brubaker & Cooper, 2000, pp.10). Common sense pertains to everyone and the concept of identity, as Brubaker & Cooper (2000) define it, also pertains to everyone. A combination of these definitions will direct the exploration of how the participants with Albinism view themselves.

The framework provides a theoretical point of view which expands our understanding of what is commonly known about identity. “Theory creates awareness on our part that ...we inject a host of assumptions” (Crotty, 1998, pp.17). Assumptions are our core knowledge base and clarifying them adds purpose to the research. Wetherell (1996) and Brubaker & Cooper (2000) noted five assumptions that underpin the psycho-social group theoretical framework:

- The psyche exists.
- Identity is a cognitive phenomenon.
- Identity is a process that is based in the psyche.
- The fundamental characteristic of identity is intrinsic and non-tangible.
- Identity is universal to humans.

The area of research called Ontology demands a clear understanding of what is the subject matter that is being scrutinized (Crotty, 1998). The researcher’s critical analysis of identity is incomplete without a thorough ontological understanding of the assumptions that predicate the term ‘identity’.

### **2.3.1 The psyche exists**

The psycho-social group framework makes several assumptions, the most important being that the psyche exists. The existence of the psyche is a prerequisite for identity.

The concept of an individual's psyche was introduced into mainstream by Freud in 1939 when he advocated the existence of two levels of consciousness namely the conscious mind and the unconscious. Jung (as



cited in Snowden, 2006) was in agreement with Freud (1939) that the conscious mind is that part which is aware of its own thoughts and actions. Both agreed that the unconscious influence thought and behaviour. Freud's (1939) focus on drive theory primarily states that behaviour is motivated by the need to satisfy primary instincts and decrease anxiety. This is a core characteristic of Festinger's (as cited in Slater, 2004) theory of cognitive dissonance. Festinger (as cited in Slater, 2004) believed that people are driven to resolve cognitive dissonance, resulting in a shift of value systems.

Freud (1939) saw the unconscious as that part which is repressed. His view has merit although his views are somewhat pessimistic. Jung (as cited in Snowden, 2006) expanded this understanding to what is now widely known as a personal unconscious, unique to the individual's experiences. For the purpose of this study, the widely accepted definition of psyche as defined by Jung (as cited in Snowden, 2006) will be used. "Jung tended to use the word 'psyche', meaning the mind, soul or spirit – a term which covered both the conscious and the unconscious processes... Jung insists that the psyche is...everything that we are aware of is perceived and interpreted through the brain. In effect, the psyche is the only reality" (Snowden, 2006, p.14). Thus, reality for the participants is personal. The psyche houses the reality of the individual and their identity that is shaped by that reality.

### **2.3.2 Identity is a cognitive phenomenon of the collective unconscious**

The psyche consists of conscious and unconscious mechanisms. Part of their reality, that can never be known to the individual, would form part of the social unconscious (Ormay, 2011). The social interaction regularly encountered by individuals, through the social identity, is the primary organiser of the individual's inner psychic life. It forms the foundation of their reality and personal identity.

Inevitably the existence of the psyche assumes that the mind exists. The mind encapsulates all those items in the conscious and unconscious. The prevalence of the conscious and unconscious is an important assumption in the psycho-social group framework. "Jung saw the collective unconscious as

the true basis of all individual psyche” (Snowden, 2006, p.48). The collective unconscious is common to everyone and is the seat of the social identity (Snowden, 2006). Individual understanding of the social identity evolves through their perception of reality. The integration of understanding into their psyche makes the experience meaningful through their own cognitive interpretation of the encounter with the social identity.

The perceiver processes the information within her own mind (Wetherell, 1996). Erikson (1974) referred to identity as a self-concept. Identity is a concept that each individual has within herself about herself. The individual is solely engaging in the processing and formulating her own identity which ultimately results in an idea that she holds about herself. According to Brubaker & Cooper (2000), an individual can possess an identity cognitively, without conscious awareness of its presence. Identity can exist as part of our unconscious yet still influence our perception and behaviour.

### **2.3.3 Identity is a process based in the psyche**

The existence of the psyche and identity is based in the collective unconscious (Giddens, 1991). Identity as a cognitive process based in the psyche is inferred because it is governed by the collective unconscious. “Social interaction and the perception of others have to be organized, ordered and simplified...” (Wetherell, 1996, p.194). Information received by the psyche is processed by the individual to make sense of reality. Information processing is subjective and biased to the person formulating their reality, as an accumulation of lived experiences that has been organised inherently (Giddens, 1991).

“No other inner agency could accomplish the selective accentuation of significant identifications throughout childhood and the gradual integration of self-images which culminates in a sense of identity” (Erikson, 1974, p.208). Through information processing, the individual identifies with items that have value and are integrated into the psyche. These selections impinge the individual’s formulation of ideas about herself, contributing to her identity formation.

### **2.3.4 Identity is intrinsic and non-tangible**

The nature of identity processes is subjective (Wetherell, 1996). Identity, as a concept, is intrinsic to the individual (Brubaker, 2000). Intrinsic is non-tangible in that it is unable to be touched. Information processing changes the individual's thought process as ideas are integrated, meaning is added to social interaction, shaping the identity of the person defining 'who am I' (Woodward, 2000). For the purposes of this study, it is assumed that an identity that is intrinsic to each participant exists. Personal identity can be tangibly measured and analysed through social expression and understanding the world as a reality for each participant. The other's evaluation of any target is subjective and tend to be self –protective.

### **2.3.5 Identity is universal**

The assumption of universalism prescribes that despite each individual receiving and processing information solitarily, all information is processed in the minds of people in the same way (Wetherell, 1996). The collective unconscious is prevalent in everyone and presents itself in the same way in the unconscious of individuals. Exploration of the social unconscious can be achieved in the group setting because it abides by the same precepts as the unconscious (Nitzgen, 2011).

## **2.4 DEFINING GROUP IDENTITY**

Foulkes (as cited in Dalal, 2002) explained that a group is made up of many people. McDougall (1921) emphasised that a group is not merely the physical composition of bodies but instead a group is composed of a collection of minds that share commonalities, thus comprising a group mind. The concept of a group mind was introduced in 1896 by Le Bon who explained groups as influenced by the psychology of crowds (Gantt & Agazarine, 2011). Although mainstream traditional psychological processes are associated with the conscious and unconscious mind of an individual, the group mind is considered to be primitive and expressed the most primal instinctual patterns of behaviour. It is this group mind that "... influence, inform and constrain what takes place in the individual" (Dalal, 2002, p.113). Essentially the group mind

guides the behaviour of each individual that comprise the group, partaking in qualities specific to that collective mind. The collective mind contains both conscious aspects and the social unconscious (Gantt & Agazarine, 2011). Defining group mind for the purposes of this study requires a broad explanation to encapsulate group identity.

Le Bon's (1896) explanations of group mind in crowd psychology which is not compatible with group identity in Albinism because he focuses on collective action. McDougall (1921) considered society as a collective but his emphasis was on the nationalism of group mind. Individuals thinking in the same way about their country is pertinent to this study in terms of social identity but he overlooks the personal identity.

The researcher has chosen a comprehensive definition of group mind as "...we conceptualize the group mind as the interdependent processes within and between the person, member, subgroup and group-as-a-whole that regulate the flow of energy and information within the system of the...group" (Gantt & Agazarine, 2011, p.105). Interdependent processes refer to those psychological processes that occur within the mind of the individual and between the minds of different people. "We may fairly define mind as an organised system of mental or purposive forces; and, in the sense so defined, every highly organised human society may properly be said to possess a group mind" (McDougall, 1921, p.9). Thus these processes testify to the fact that the group mind is a psychological entity that can persuade changes within the individual and can be affected by each individual (Gantt & Agazarine, 2011). The group mind exists prior to the individual and after death as a perpetuation of society. Thus, the group mind can exist in the unconscious (Ades et al., 1972).

"We can perceive ourselves as a member of a social group and as someone with the characteristics of the group" (Wetherell, 1996, p.33). Self-categorization is an extension of the personal identity and can facilitate the person's differentiation from or identification with a group identity (Wetherell, 1996). Self-identification with characteristics of a group can transform the

person's psychological processes when in a group setting. The personal identity of an individual can submit entirely to the group identity or aspects of their personal characteristics can be carried out in the group situation depending on the ego strength of the individual (Wetherell, 1996). In either context the personal identity accommodates the social identity thus transforming the individual into a group member. Transformation from individual to group member may not be a conscious relinquishing of personal identity in favour of the group identity. It is rather the inevitable consequence of interdependent processes through self-categorization (Wetherell, 1996).

Group identity exists in the group mind as a psychological process. The researcher defines group identity as a specific collective identity that depends on both the social identity and the individual's personal identity. "For a group identity to be viable and meaningful, the group boundaries must be well defined, and there must be a recognizable "out-group", that is, those who do not belong to the group...people seek more exclusive memberships that entail strong socio-identities and struggle with other observable groups" (Badad, Birnbaum & Beene, 1983, p.100). Clear criteria are stipulated that must be met for a personal identity to exist as a group identity. This study will explore the possibility that a group identity exists amongst girls with Albinism. The evidence that a group identity does exist means that the above stipulated criteria will be met amongst the group members.

Badad et al., (1983) noted, firstly, that well defined boundaries of the group identity must be clearly delineated for a minority group identity to be authentic. Delineation is a social criteria that exists, for the group to exist as a tangible entity. Authenticity of the group boundary can be upheld either by group members or by broader society, having enforced a limitation onto the group. Prejudice, stereotyping or traditional beliefs, for example will separate the group identity from other identity groups.

Secondly, a clear and distinct out-group must be obvious (Badad et al., 1983). Out-group is defined as those people who do not share in the group identity with the group members. The significance of this out-group is that they are

considered to be excluded from the group identity by those members of the in-group. Out-group is purely a perception of the group members and may not see themselves a unified group as defined earlier. Non-members from the group are comprise the out-group merely as a categorical placement. Individuals who do not identify with the distinguishing characteristics that define a specific group identity, can distance themselves from that group, either through action or direct verbal communication.

Thirdly exclusive membership to the group based on social identity speaks entire from the perception of that individual who does identify with the group identity. Recognition of the social identity by other people is a prerequisite for self-identification as a member of an identity group. The social identity needs recognisable traits to be identified by others. Identification with the social identity of another person is from the self. Recognition of the social identity but also identifying with its defining characteristics is part of the self-identification of other people to form a group identity. Self-identification creates a sense of belonging that is intrinsic. This sense of belonging can evolve from attachment ties which limits group membership (Smith, 2007).

The fourth criteria to be met for a group identity to exist is a struggle with an observable group (Badad et al., 1983). This does not necessary stipulate that the struggle is with the out-group. The researcher interpreted Badad et al. (1983) meaning that the struggle with an observable group can include siblings, peers or family members.

#### **2.4.1 Development of group identity**

Group identity development processes are subjected to the same operational mechanisms as with individuals because "...the very same dynamics found in the individual apply to collective mental processes-group, institutional, or social" (Tuber-Oklander, 2011, p.63). Understanding group identity development is a complex developmental pattern that incorporates the social and personal identities. Personal relationships and meaningful social experiences plots a unique growth course for each individual. Yet, every individual cultivates an identity via the same method of information processing

(Wetherell, 1996). Processes of group identity development informs this study of how identity is formed intrinsically to each person via the widespread social identity. Interpersonal dynamics with the social identity formulates a group identity and governs behaviour of group members.

This literature review will unpack group identity development using psychoanalytic theories of social identity and personal identity. "Psychoanalytic thinking could well contribute to... ways in which segments of modern society... understand, conceptualize, and use spontaneous trends of identity formation" (Erikson, 1974, p.18). Group identity development depends on the social identity that is conceptualized in the society. Psychoanalysis offers this study a developmental framework to understand the concept of identity in society, personal identity and group identity.

#### **2.4.2 The social identity in society**

Social identity exists prior to the personal identity as tradition and beliefs (McDougall, 1921). Each person is born into a group and thus into a social identity that already exist (Dalal, 2000). "Social identity involves the process whereby the individual becomes part of a social group and the group becomes part of the individual's self-concept" (De La Rey, 1991, p.44). This circular social interaction between the group, social identity, the individual's self-concept and personal identity illustrates a dynamic interpersonal and intrapersonal interaction. The social identity of society is integrated by the individual. Individuals adopt the values of society, learning through social interaction, which sustains the traditions of the social group. Social identity can be understood independently of any specific cultural norms as a secular perspective of the society.

Social identity is based in the collective unconscious which is made up of traditional beliefs and archetypes that is not specific to the individual. The collective unconscious is common to all people in society, independent of personal experiences. "Jung saw the collective unconscious as the true basis of all individual psyche" (Snowden, 2006, p.48). The collective unconscious extended beyond the individual psyche and includes the group mind. Firm

beliefs of the group mind are inherited over centuries predicated a baseline to guide acceptable behaviour of a group (Le Bon, 1896).

The collective unconscious shapes the social identity of the group mind through cognitive processes (Wetherell, 1996). Several cognitive mechanisms of sustaining the widespread social identity have been identified by theorists. "Self-categorization, social identity, group membership and conformity can now be seen as addressing related issues" (Wetherell, 1996, p.40). The cognitive processes of self-categorization, social identity, group membership and conformity causes a cognitive shift in the individual, surrendering the personal identity to the social identity through social interaction (Wetherell, 1996).

The main function of self-categorization is to determine group membership. Each individual will categorize others into the metaphorical box but simultaneously the individual categorizes herself (Foster & Louw-Potgieter, 1991). Self-categorisation emphasises the similarities and differences between the self and others. The in-group and out-group are separately classified relative to the self. The self is either placed into a social group and aligned as a group member or is alienated from group membership (Foster & Louw-Potgieter, 1991). Self-categorizing can also be referred to as self-stereotyping (Wetherell, 1996) or identification (Brubaker & Cooper, 2000). Identification is a subjective term that incorporates the concept of identity (Brubaker & Cooper, 2000). Identification encompass elements of commonality, connectedness or the sense of belonging. Identification only occurs within certain contexts (Giddens, 1991). Identification is partial because it uses projection as its mechanical operation (Giddens, 1991). During these instances of identification the individual can adopt traits or patterns of behaviour that is prevalent within that social context. Interpersonal and intergroup behaviour are governed by differing psychological mechanisms which are located in the self-concept. De Le Rey (1991) defined the self-concept as containing both the social and personal identity. Thus the extent to which the personal identity is surrendered to the social identity will determine the interpersonal and intergroup behaviour of the individual. The



individual justifies her behaviour at a psychological level depending on the motivation for the behaviour (Foster & Louw-Potgieter, 1991).

The strength with which social identity can dominate the personal identity of the person demonstrates the extent to which the self-categorization of the prevailing group identity can conform the behaviour of each group member (Foster & Louw-Potgieter, 1991). "Conformity helps ensure the uniformity of the group, and conformity itself comes about because of a need to validate beliefs" (Foster & Louw-Potgieter, 1991, p.405). Conformity is that aspect of the social identity that allows the perpetuation of the beliefs and traditions of the group. The shared identity of a social group influence individuals through the mechanical elements of belonging, the mind, and prejudice (Dalal, 2002).

Stereotyping and prejudice are congruent to conformity and are conceptualized as irrational phenomenon located in the unconscious (Foster & Louw-Potgieter, 1991). Together they distinguish the in-group from the out-group (Foster & Louw-Potgieter, 1991). Irrational beliefs are externalised through projections and become resolute ideas about the out-group (De La Rey, 1991). Those who comply with the traditions and values of the in-group and those who stereotypically do not comply are excluded from the in-group and constitute the out-group. Tradition is essentially knowledge and information that offers a way of organising social life (Giddens, 1991). Social interaction is guided by tradition because it creates a sense of stability through group norms, stabilizing its group members. The individual may adopt behaviour patterns of the broader social identity as a strategy to resolve anxiety or diminish anxiety-creating patterns (Giddens, 1991). Increased anxiety leads to increased security behaviours (Greenberg & Mitchell, 1983).

Le Bon (1896) first identified the loss of individuality in his theory about crowds. Deindividuation is the loss of individuality to the group (Foster & Louw-Potgieter, 1991). This implies that the social identity completely dominates the personal identity. Le Bon (1896) describes the primitive and irrationality of crowds as an absence of impulse control. A collective mind dominates, controlling the behaviour of each individual within a crowd (Le

Bon, 1896). This primitive and collective mind has a heightened capacity for aggression and even violence. Aggression and violence can be directed at minority groups as a result of regressive group phenomenon. Volkan and Kernberg (as cited in Dalal, 2002) identified several characteristics of regressive group phenomenon as follows:

- A loss of individuality and autonomy of the individual group member
- Absolute submission to a group leader
- A polarize outlook presents as an 'us' vs. 'them' mentality or absolute 'good' and 'bad'
- A devaluing of the 'other' group
- Blurred reality or magical thinking
- Collective, paranoid expectations or shared, depressive feelings
- Group scapegoating by the majority group.

Regressive group phenomenon is the result of deindividuation. An individual can be drawn into a mass regressive group which can destroy individual autonomy (Dalal, 2002). Deindividuation is the complete surrender of the personal identity to the social identity.

#### **2.4.3 Personal identity**

The personal identity and social identity interplay within the individual and is difficult to differentiate. The boundaries between social identity and personal identity can be blurred. Personal identity arises through personal experience with the social identity. "The means by which we differentiate ourselves from other people in our lives as well as from our own organic functions constitutes the very core of our experiences of personal identity." (Kroger, 1993, p.6). Personal identity is not independent of others but merely a chosen difference to demonstrate our individuation from others.

Personal identity is based in what Jung (as cited in Snowden, 2006) referred to as the personal unconscious. The personal unconscious arises from personal experience with the social identity. The personal unconscious is not inherited like the collective unconscious, but is gained through social

interaction. Each person has a unique personal unconscious (Snowden, 2006).

Erikson's psycho-social identity development theories informs this study of the mechanism of the identity formation in the personal unconscious (Kroger, 1993). Erikson (1974) explains that teenagers are expected to be in the stage of identity crisis. He called this stage Identity versus Role Confusion (Kroger, 2007).

**a. *Interpersonal dynamic between personal and social identity***

The dynamic interaction between the social identity and the personal identity of the individual has an underlying psychological mechanism. "Psychodynamics describes the kinds of unconscious psychological mechanisms that are involved- introjection, identification, projection and projection identification" (Wetherell, 1996, p.111). These operational mechanisms facilitate the interplay between the outside social identity and the internal personal identity. The social identity shapes the personal identity through social interaction utilizing these psychodynamic mechanisms.

Introjection is a fundamental, yet primitive, stage in the psycho-social development of identity formation. It is the rudimentary incorporation of another's concept into the self (Erikson, 1974). Essentially introjection is an acceptance and mirroring of the social identity during the early stages of identity development.

In terms of personal identity, identification is the internalisation of the projection of another. It is a personal experience that impacts on the individual's mind. Children, initially identify with those characteristics in people that affect them. This gives way to more realistic judgement as mature identity formation is attained in adolescence. The individual can incorporate selective aspects of childhood identifications which can be acquired from social group sources such as families and communities, shaping the values, norms and standards of the adolescent (Stevens & Lockhart, 2011).

The psycho-social identity developmental model considers adolescence as the maturation phases of identity formation. It is the final phase in the development of the personal identity and is the end result of introjection and identification (Erikson, 1974). Puberty is the stage of self-definition. Identity formation during this phase is the individuation of the personal identity. Identity formation matures when identification ceases to be useful and incorporates both projections and projection identification.

Projection is a psychoanalytical defence mechanism assigned to the individual. Individuals reject aspects of themselves and impose them onto others. Internalizing the projections of the collective unconscious undermines a coherent sense of self (Allen & Fonagy, 2006). Identification with these projections can be countered by the family who is able to reduce the child's anxieties. Failure of the caregiver to contain a child's anxieties increases vulnerability to projection identification. Mature identity formation in adolescence is a resolution of these projection identifications and a dissipation of the identity crisis.

***b. Interpersonal psycho-social development of personal identity***

Attaching meaning to social experiences shapes the personal identity of the individual. Intrapersonal maturation changes the meaning that the individual adds to social experiences. The maturation of personal identity is developmental. "Identity work...brings resolutions to earlier psycho-social stages of Trust Versus Mistrust, Autonomy Versus Doubt and Shame, Initiative Versus Guilt and Industry Versus Inferiority into focus as youth encounter the work of learning how best to recognize and actualize their own individuality within a larger social order" (Kroger, 2007, p.9). Adolescent identity work aims to resolve earlier psycho-social stages in order to facilitate maturation into adulthood.

The resolution of each stage indicates the negotiation of polarities, determining a balance that is ideally tilted towards the more positive outcome.

A resolution of each previous stage presents an end result in adolescence within a final psycho-social stage called Identity Versus Role Confusion.

Trust Versus Mistrust results in the teenager as learning how to manage the world optimally (Kroger, 2007). The early developmental stage of trust versus mistrust inevitably resolves itself as a representation of hope (Kroger, 1993). "The child comes to know itself in relation to another and gains a sense of inner continuity, sameness and trust in itself and its developmental partner" (Kroger, 1993, p.20). Developmentally the stage of Trust Versus Mistrust is reliant on the role of the primary caregiver to form secure attachment relationships.

The resolution of Autonomy Versus Doubt and Shame determines the conviction that one has to express oneself (Kroger, 2007). "Social responses to *will* has the potential to instil either an increased confidence in a child's capacities or an enduring sense of shame and doubt" (Kroger, 1993, p.22). The determination of the child can resolve itself in adolescence as a sense of independence and a belief in their ability to master a skill. "Shame becomes a central possibility, arising from the individual's perception of her own attributes being a defiling thing to possess and one she can readily see herself not possessing" (Goffman, 1975, p.18). Unresolved shame presents itself when the adolescent rejects an aspect of herself.

Initiative Versus Guilt stage of psycho-social development resolves itself to present as a basic sense of competency, self-reliance and realistic ambition (Erikson, 1974). This psycho-social stage is associated with the ability to "...translate thought into action...From initiative grows a sense of purpose and ambition vital to tasks of adolescence and adulthood" (Kroger, 1993, p.23). Self-motivation during adolescence is an indication that this stage of identity development has been resolved. Adventurous adolescents with adaptable ways of reasoning have gained mastery over this psycho-social stage.

Industry Versus Inferiority lends itself to accomplishment and mastery of skills when resolved (Erikson, 1974). "Industry has been described as an

apprenticeship to life; feelings of competence and achievement are the optimal results here" (Kroger, 1993, p.23). Mature integration of this developmental stage presents as a socially proficient adolescent that is able to explore various roles in her personal and vocational life. The adolescent is able to interact socially in a mature yet individuated way that is goal directed (Nielsen, 1996).

Identity Versus Role Confusion is a mature adolescent phase where the individual uses advanced cognitive reasoning to resolve this psycho-social phase. Society demands mature adult behaviour in appropriate roles. The prevalence of Role Confusion can be attributed to the lack of committing oneself to anything that defines oneself absolutely as 'who I am' (Kroger, 1993).

### ***c. Gender specific identity development***

Nielsen (1996) wrote that girls were more likely to enter adulthood without resolving important identity issues thereby not fully attain identity formation. The primary reason attributed to this phenomenon was that identity formation requires 'unfeminine' behaviours. Among these, the following were reasons noted for unresolved issues: a lack of taking risks, an absence of questioning authorities, lack of asserting opinions and not putting personal needs and interests ahead of others' expectations.

Girls are also found to have more social skill and social reasoning than boys at the same age (Nielsen, 1996). This social awareness makes them susceptible to the social messages and conditioning than males. "...most teenaged girls shape their identities around their fears of being abandoned by people for being too self-centred, too outspoken, too demanding, too self-reliant or too assertive" (Nielsen, 1996, p.220). Connecting with others and a sense of belonging is particularly important to female teenagers. In order to fit in the female teenager is more likely to adjust her behaviour to gain the approval of others (Nielsen, 1996).

#### **2.4.4 Group identity in adolescence**

The development of group identity during adolescence is dependent on the teenager's individuation from family and her ability to form social friends. "For adolescents, friendships and peer groups provide a further important context for later identity development...criterion for friendship during early adolescence is enlarged so that friends are likely to share interests, values and beliefs" (Kroger, 2007, p.54). Social groups offer the teenager an important platform for identity development within a broader social context outside of the family. Teenagers can evaluate their value systems and explore new interests and beliefs with others within their peer group. Through this social interaction the adolescent develops a sense of Self through social testing in various other contexts (Kroger, 2007).

Group identity introduces a new stage of psycho-social identity development during the teenage years. "Most adolescence will experience feelings of both belongingness to and alienation from particular social networks at the same time. Resolution of this group identity versus alienation crisis serves as a prelude to the later Identity Versus Role Confusion crisis" (Kroger, 2007, p.56). Adolescents can either conform or be alienated from a group identity. This depends on the individuation of the adolescent and the mature ability to adapt her reasoning within social contexts. Determining that the group identity will be adopted and integrated gives the adolescent a feeling of belonging.

#### **2.5 UNDERSTANDING ALBINISM**

Understanding Albinism is complex and differs according to the framework that is applied. Albinism has a medical definition, a sociological definition, a cultural and personal definition according to how those with Albinism define themselves.

Albinism, essentially, is a medical classification of a genetic abnormality that results in a reduction in the synthesis of melanin within the melanin pigment system (R. King & C. Summers, 1988). The skin, hair and eye colour can be affected by the reduction in melanin synthesis. The medical model defines Albinism in terms of genetics and the presentation of the abnormality and the

severity of oculomotor impairment (King & Summers, 1988). Thus, Albinism is a diagnosis to explain the rare presentation of unusual symptoms. The medical model overlooks the human existence of the person that lives with this unusual presentation of symptoms.

The definition of Albinism changes in the context of social constructs which is based on the interaction with others. This interaction with Albinism is based on the value system of the social identity. How others react to and interact with the lack of pigmentation of Albinism will essentially impact on personal identity and define the person as an Albino.

Albinism is a condition that has meaning to those with the condition. Mongezi Ngidi, a Bachelor of Arts graduate from UKZN, wrote an autobiography about his life living with Albinism whilst in his twenties and stated: "I will admit that it took me a very long time to find myself and to understand what my condition is all about" (Ngidi, 2005, p.2). His search for understanding adds personal meaning in living with Albinism which is overlooked by the medical diagnosis of a genetic melanin deficiency abnormality.

Ngaire Blakenberg (2000) wrote of her experiences growing up as a singular Albino. She wrote of how people watched her "...people came from all over to look...with their eyes following me always" (Blakenberg, 2000, pp.7). Her experiences are supported by a study conducted in Limpopo by University of Venda students. The study concluded that early life experiences for people with Albinism were difficult and that in their teen years Albinos looked for group interaction and acceptance (Gaigher et al., 2002, pp.9)

Growing up as the only Albino, Blakenberg (2000) writes about her experiences of living with Albinism. Her work explores the psycho-social impact of Albinism: "My experience is not one that can be easily universalized, or even collectivised: It is a lonely identity path" (Blakenberg, 2000, pp.6). Blakenberg (2000) speaks of loneliness and isolation but never rejects her Albinism. Ngidi (2005) wrote that he could not imagine living without his



Albinism because it is core to defining himself as a person. This demonstration of pride has value in identity formation.

Ngidi (2005) explains that social interaction with others was difficult because of his Albinism. "My life-changing experiences include discrimination, in the form of racial prejudice, and solely because of my Albinism condition" (p.2). People react to the physical presentation of Albinism with adverse judgements. Ngidi (2005) states that this negative interaction presented challenges to him which guided his life. The role that Albinism played in his life defines who he is, thus shaping his Albino Identity. The reason for this is explained by Gaigher et al. (2002) who concluded that "in addition to managing the physical condition, Albinism affects relationships with family and friends...and perhaps most importantly one's sense of self and the relationship with one's own body" (pp.10). Thus, Albino Identity will envelop relationships with significant loved ones, friends, family and the self-concept.

## **2.6 ALBINO IDENTITY**

This study aims to explore if Albino Identity exists as a group identity. Albino Identity is the identity status of those persons with the medical condition of Albinism. Albinism is a genetic condition that presents as an absence of melanin production in the body. This has meaning and identity value to those living with Albinism. Albino Identity is a separate and recognisable social identity. Goffman (1975) states that it is not merely the difference that is powerful enough to impact on personal identity but that it is the visibility of that difference to others that warrants a social reaction. He further stated that stigmatisation is a unifying factor amongst those who are ostracised.

Blakenberg (2000) interviewed individuals with Albinism and presented her findings from an African cultural perspective, defining what it means to an Albino, to be black and Zulu. This study focuses on the human psycho-social aspects of Albino Identity within a cultural social group context. In this study, however, the subjective experiences of the participants will be considered independent of culture but rather as a fully immersed human perception.

Blakenberg (2000) defined Albino Identity according to the following parameters:

- Spiritual delineation of Albino Identity (ancestral wrath)
- Increased cultural protection and increased differentiation of Albino
- Albino had a greater awareness of self within racial contexts
- Definitive impact of family reaction and participation in shaping Albino Identity
- Sense of belonging, community and security is determined by the family
- Primary cultural and racial identification is with family
- Social acceptance is an important aspect of Albino Identity.

Blakenberg's (2000) findings in her research applied to persons with Albinism who had never met each other. Yet, each participant presented with the same parameters that delineated Albino Identity. This indicates that Albino Identity, as a personal identity, is created by an unwritten societal value system that governs the interaction between society and those with Albinism.

### **2.6.1 Albino Identity is created by the social identity in society**

Albino Identity is a personal identity of those persons with Albinism. "One's personal identity will have contributed to ...the personal way in which social identity is acted out" (Wetherell, 1995, p.40). The personal identity can be identified as those aspects, attitudes or thoughts that alters the behaviour of the individual. The personal identity is merely a personal reaction to the social identity. Each Albino's opinion of their interaction with the social identity's opinion of Albinism will constitute a personal Albino Identity. The social identity will exhibit a value system concerning Albinism but the Albino's response and ideas about that value system will determine the way that the social identity is acted out by the Albino.

Blakenberg (2000) and Ngidi (2005) describe encountering the same value system towards Albinism, as dictated by the social identity. The most prevalent social experiences incorporated the categorical limitations such as

myths, prejudices and racial stereotyping. Psycho-social reconstruction of the person with Albinism's self-concept and personal identity to include categorical limitations imposed by others. "Social and personal identity are part, first of all, of the other persons' concerns (or perceptions) and definitions regarding the individual whose identity is in question..." (Goffman, 1975, p.129). Albino Identity is created by the social identity's opinion of Albinism. These opinions are reflected, adjusted and integrated by the person with Albinism. Blakenberg (2000) uncovered in her research that others have an unreasonable emotive reaction to those with Albinism. "...the variety of social/community responses to Albinos ranging from adoration and overprotective to fear and loathing" (Blakenberg, 2000, pp.16). This response reflects the social identity and the other's opinion of the Albinism regularly encountered by Albinos.

The person cannot remain unaware of the other's opinions of her Albinism but is compelled to acknowledge it and deal with it as a part of her self-concept as an Albino. Ngidi (2005) demonstrate awareness of the other's opinions of the colour of his Albinism. He reconstituted his view of his Albinism, shifting from a medical condition to concentrate on the colour. "...Albinism is not just a condition defined by a lack of colouring in the body. Instead, Albinism can be seen as showing us the "colour" which defines us all as human beings first. Albinism is the "colour" within being" (Ngidi, 2005, p.23). According to Ngidi (2005) Albinism is meaningful to those who live with it because it changes the colour of the individual due a lack of pigmentation. The colour that Albinism presents in the skin, hair and eyes is fundamental in his self-concept as a semblance of humanity.

Individuals possess a personal identity that is influenced by "... the multiplicity of selves one finds in the individual in looking at him from the perspective of social role..." (Goffman, 1975, p.81). Ngidi (2005) in his biography described his intense awareness of the contrasted ways in which others saw him, including his mother, his community, his school and even Nelson Mandela when he met the icon. The meaning that he extracted from these multiple sources is that the colour of Albinism is what has distinguished himself as an

Albino. Blakenberg (2000) reiterates this saying that others are afraid of the colour of Albinism. The way that the other responds to the colour of Albinism is indicative of a group mind that informs them of what to think.

The significant impact of these societal values in determining Albino Identity demonstrates the profound shaping of the social identity. "But it is maintained that a society, when it enjoys a long life and becomes highly organised, acquires a structure and qualities which are largely independent of the qualities of individuals who enter into its composition and take part for a brief time in its life. It becomes an organised system of forces which has a life of its own, tendencies of its own, a power of moulding its component individuals, and a power of perpetuating itself as a self-identical system..." (McDougall, 1921, p.9). McDougall (1921) refers to a method that replicates thinking for the purpose of sustaining a specific system. This explains the similarities between the experiences that Blakenberg (2000) and Ngidi (2005) reported. According to Ngidi Blakenberg (2000) the Albino Identity is forged around issues including myths, rejection, isolation, acceptance and family protectiveness. Each aspect of Albino Identity was reiterated by Mongezi Ngidi (2005). Opinions that the social identity have about Albinism governs the behaviour of the other towards the Albino. The amount of influence that others have on the development of Albino Identity depends on the individual's ability to resolve these issues in each psycho-social stage of identity development.

Constant interaction with the other's perception of Albinism shapes the self-concept of the Albino. Self-concept is the primary concern of identity development. The psycho-social stages discussed earlier in the development of personal identity includes: Trust Versus Mistrust, Autonomy Versus Doubt and Shame, Initiative Versus Guilt, Industry Versus Inferiority and Identity Versus Role Confusion. These apply to the development of Albino Identity as a personal identity. The researcher also included Alienation Versus Group Identity as a final psycho-social maturation stage in group identity development for the purposes of this study.

Ngidi (2005) describes his Albinism as giving him purpose in his life and that he strives to uplift others with Albinism. He writes of trust/hope, representing resolution of the first psycho-social stage of Albino Identity development. Blakenberg (2000) described a struggle with the societal reaction to her Albinism stating that those with Albinism have to strive continuously "...disproving the negativity and prove that he/she is a capable human being" (Blakenberg, 2000, pp.25). This struggle for independence is indicative of resolution of the second stage of psycho-social development. Ngidi (2005) writes with confidence of his determination to achieve and prove himself. Blakenberg (2000) and Ngidi (2005) have both proven their mastery of skill and initiative by graduating from university with a Master's degree and Bachelor's degree respectively. Yet, both authors attribute their identity status to Albinism. Albinism increased their will and determination due to the social responses. The development of their personal identity was based in Albinism.

Ngaire Blakenberg (2000), describes people with Albinism as "that rare and random tribe" (pp.1). Albinos are described as a separate and unique group with their own values, beliefs and group identity. The widespread social identity is fundamental in creating Albino Identity as a minority group identity according to the above mentioned categorical limits of prejudice, stereotypes, and mythical archetypes. "The (minority)...person, always needs to be understood through the terms of these categorical groupings, that is, through how they are thought to differ from the norms of the dominant culture. Put differently, this is a categorical fixing of certain identities that ties them to a set of prejudicial stereotypes...a prejudicial fixing of identity" (Ratele & Duncan, 2003, p.121). Individuals integrate beliefs from tradition which guides their behaviour and perceptions within the broader group towards minority groups such as those with Albinism.

The Albino may be considered a minority person due to the rare nature of the condition. All minority groups exist within broader classification classes because of a stereotypical difference that the wider group uses to identify the minority as separate. Therefore, the wider group allocates a single criteria to the minority that defines their social identity within that larger group. The

minority person interacts with the 'prejudicial fixing of (her) identity' by the other and integrates the experience by extracting meaning (Ratele & Duncan, 2003). This meaning forms the foundation of Albino Identity that is based in difference from the broader society due to Albinism.

### **2.6.2 Albino Identity is based in non-conformity**

Social norms play the role as standardizing social interaction. Primarily, norms are responsible for laying a stable acceptable foundation for group interaction. (Slater, 2004). Group norms emerge to provide the individual with a frame of reference. This frame of reference guides acceptable behaviour and attitudes and maintains uniformity. Uniformity ensures the continuity and progression of the group. Social norms dictate the behaviour of those who share in the group mind.

Blakenberg (2000) writes of Albinism in African communities as a "wild whiteness" (pp.2). African girls with Albinism are unable to conform to the standard of normal pigmentation prevalent in their communities due to the lack of melanin production that characterizes Albinism. Ngidi (2005) professed the importance of the different colour in Albinism due to a lack of pigmentation. Others respond to this colour because it represents a difference that is against the norm. Blakenberg (2000) explains that people are afraid of Albinos because it is a fear of a different colour. Fear is experienced as anxiety (Greenberg & Mitchell, 1983).

Non-conformity with the social norm impacts on the group mind sanctioning an action from the other. "The search for understanding lead members to believe that social reality is the standard and that any departure from unanimity is intolerable because it undermines a stable basis for beliefs" (Mann, 1969, p.36). The social being has to decide on the acceptability of the lack of pigmentation presented by Albinism. Determining the level of intolerance of the non-conformity is based in the group mind.

The demand on the social being to resolve the social norm contravened by Albinism is an ambiguous state. "People conform to a group norm when they

are in an ambiguous situation, and when the response required from them is unclear, because the group norm serves as information (or validation) for their response" (Foster & Louw-Potgieter, 1991, p.405). The existence of Albinism as a non-conformity ultimately leads to an invalidation of beliefs. Festinger (as cited in Slater, 2004) termed it cognitive dissonance and defined it as "the psychological opposition of irreconcilable ideas (cognitions) held simultaneously by one individual..." (p.113). Festinger (as cited in Slater, 2004) believed that dissonance continues to prevail in the psyche of that individual who hangs onto belief such as 'All Africans are a certain colour'. The concept of contrasting ideas in one individual is so unbearable that the individual needs to solve the conundrum "...created a motivating force that would lead, under the proper conditions, to the adjustment of one's behaviour to fit one's belief" (Slater, 2004, p.122). Blakenberg (2000) and Ngidi (2005) wrote about the reconciliation of ideas that others had as the beliefs that they each encountered socially including traditional myths, stereotypes and prejudices.

The ability to reconcile conflicting ideas will govern their ability to adapt and resolve dissonance. Adaptability which is defined as the ability to create new paradigms (Slater, 2004). The researcher believes that adaptability to the existence of an Albino by no measure implies acceptance of the person with Albinism. Adaptive responses may require courage, resolution and novel initiatives to overcome the anxiety that is correlated to danger (Giddens, 1991). Danger may be a displacement of hostility from the social unconscious onto minority targets such as non-conformers (Duckitt, 1991). Hostilities can cause growing anxieties which can be prevented by projections such as tradition myths (Giddens, 1991). Traditional beliefs from the social unconscious can resolve the threat of anxiety (Giddens, 1991). Contrary, the inability to resolve cognitive dissonance will result in hostilities such as stigmatization of the minority target because she does not conform (Goffman, 1975).

### **2.6.3 Albino Identity and stigma**

Blakenberg (2000) probes Albino Identity by exploring contributing role of the community and family. However, people with Albinism are ostracized by fellow citizens as a result of their “white” appearance due the lack of pigmentation in their skin, their blond hair and blue/green eye colour (Magnus, 1992). The researcher has interpreted this as regressive group phenomenon and prejudice that is experienced by those with Albinism.

Goffman (1975) referred to social prejudice as stigma. In his book “Stigma: Notes on the Management of Spoilt Identity” Goffman wrote “By definition, we believe the person with a stigma is not quite human” (p.15). Although, it is the opinion of the researcher that the ‘not quite human’ of Goffman’s (1975) theory is intended to imply the inferiority of the stigmatised person and not a reference to the exaltations associated with the myths that surround Albinism. Yet, stigma, by its very nature, is a hostility from the group mind intended to dispel the non-conformer as a minority target.

Stigma, is defined, as a social belief system based in the social identity. The social identity brands the non-conforming Albino as stigmatized and contributes to the organisation of her psyche (Goffman, 1975). “Persons who have a particular stigma tend to have similar learning experience regarding their plight, and similar changes in conception of self” (Goffman, 1975, p.88). Stigma in the social identity conditions the personal identity by informing the Albino what she ought to think of herself (Goffman, 1975). Society’s attitude to Albinism changes the perception that the person with Albinism has of herself, underpinning Albino Identity. Goffman (1975) explains that the change in self-concept of the stigmatised person is because she will become intimately aware of how others perceive her.

The awareness of how others perceive her is created by the visibility of what Goffman (1975) termed a ‘failing’. Stigmatization is initiated by the other creating an awareness of her ‘failing’ for the minority party, changing her personal identity. “When the stigmatized person’s failing can be perceived by our merely directing attention to her-when she is a discredited... person – she



is likely to feel that to be present among normals exposes her to an invasion of privacy, experienced most pointedly perhaps when children simply stare at her. Displeasure at being exposed can be increased by conversations ... in which they express morbid curiosity about her condition ..." (Goffman, 1975, p.97). Stigmatisation may not be conscious or intentional on the part of the perpetrator, as is the case with children. Goffman (1975) writes of several agencies of social interaction that comprise the process of stigmatization. These include the exclusion of the stigmatized person; the labelling of the person as different from 'normals'; the separation of the stigmatized from the in-group and an altered method of communication of the in-group towards the stigmatized person. Through these agencies, the Albino is informed of the opinion that the social identity has of her Albinism. The meaning that the targeted person attach to this social interaction will change the personal identity of the Albino.

Firstly, the process of stigmatisation involves the social exclusion of the stigmatised individual by others. This statement has several implications:

1. More than one individual is involved in the process of stigmatisation, the person being ostracised and the person doing the stigmatizing.
2. Stigmatisation is in itself, a group process.
3. The visual accessibility of the 'failing' is the source of motivation for the 'normals' to engage in stigmatized behaviour patterns.
4. Change of behaviour of the person doing the stigmatisation puts an immediate strain on the social interaction.
5. A label is imposed onto the person being stigmatized.

The social exclusion of an individual is discrediting that person, showing distrust and rejection overtly. Discounting of the Albino is based on the visibility of Albinism in the skin, hair and eyes (Blakenberg, 2000).

Secondly, the process of stigmatisation has an element of classifying the ostracised individual as other-than-normal. Labelling is on the part of that person doing the stigmatizing and according to their world view. The label can be given to the person being ostracised verbally like name calling or through

non-verbal cues such as staring. These communications are received by the person being stigmatised who infers meaning onto the actions of others (Scheff, 2007). Albinos often received insulting epithets as a stigmatization (Blakenberg, 2000).

Thirdly, the process of stigmatisation involves an exclusion from group acceptance. According to Goffman (1975) the non-conformist is considered to be a 'defaulter' of social norms and is seen as deserving social exclusion. The researcher believes that it is not merely the withholding of acceptance but the hostile expulsion of the stigmatised person from group membership. Goffman (1975) described the hostility of the expulsion as a change in the communication with the stigmatised person.

Lastly, the process of stigmatisation involves an altered method of communication towards the stigmatised person. Communication is not only the verbal interaction within a social group but non-verbal nuances can give indications of the quality of social bonds (Scheff, 2007). Goffman (1975) coined the term "open persons" to describe the group vulnerable to random social interaction by virtue of their stigmatised status. Goffman (as cited in Fine, 2003) forged the concept of an interaction order "...to characterize the web of normative beliefs that facilitate communication and social interaction" (p.51). He further distinguished between the acquainted and unacquainted. The unacquainted need a reason to initiate an encounter. Yet, he articulates people that are considered devalued can be addressed without an explanation and their privacy can be invaded. "This issue is not merely visibility (of stigma) but obtrusiveness; this means that failure to sustain the many minor norms important in the etiquette of face to face communication can have a very pervasive effect upon the defaulter's acceptability in social situations" (Goffman, 1975, p.154). Participants in Blakenberg's (2000) study reflected on the invasions of their privacy and the aggression that they encountered regularly. They describe people as staring, invading personal space and a hostile method of verbal communication that included being called derogatory names, showing deep seated distrust towards the Albino and the intentional disgracing of the individual (Blakenberg, 2000). The

content of the communication with the Albino is reportedly not always derogatory but often based in the discussion of myths or enquiries into their appearances. Goffman (1975) explains that the stigmatized person will encounter trends of behaviour often and must adapt to learn how to manage others as evidence of the change in self-concept of the stigmatized person.

Blakenberg (2000) and Ngidi (2005) described the rejection that they encountered due to their Albinism. Rejection is not only stigmatization as seen with discrimination but it also includes alienation such as exaltation or degradations as experienced with myths. Aspects of mainstream society's group mind such as myths and stigma have contributed to the delineation of Albino Identity.

#### **2.6.4 Albino Identity and myths**

People associate Albinism with mythical beliefs (Blakenberg, 2000). Myths associate Albinism with good luck, blessings or a punishment from the ancestors. Some myths undermine the mortality of the Albino saying that Albino's disappear and do not die. Similar perceptions of others seem widespread to all Albino's interviewed by Blakenberg (2000) regardless of their location within South Africa. Beliefs exist prior to the Albino entering into that specific social situation and is thus a reflection of the collective unconscious.

Myths are traditional beliefs based in the group mind. "...all myths are a sort of projection from the collective unconscious" (Snowden, 2006, p.53). A projection from the collective unconscious implies a rejection with a constructed story, legitimising treatment of the 'cast away', validating the behaviour of the crowd (Goffman, 1975). Individuals integrate these beliefs which guide behaviour and perceptions. The extent to which the Albino psyche is shaped by the collective unconscious through personal experiences depends on the extent to which they integrate traditional mysticism.

Jung (as cited in Snowden) spent much of his time understanding myths. "He realized that myths were stories that helped people to understand common

psychic processes and the ways in which the human psyche develops ...Myths arise from archetypes, which are not intellectually invented, but are always there, forming the structure of the primordial collective unconscious" (Snowden, 2006, p.32). Myths help people deal with the cognitive dissonance caused by witnessing an Albino for the first time by justifying the existence of Albinism.

Rejection via myths and prejudice is from the collective unconscious because myths are based on archetypes and prejudice emanates instinctively. "The collective unconscious has two main aspects: archetypes and instincts...Both these components belong in the collective unconscious because they exist independently of the individual psyche and contain universally recognized, inherited aspects." (Snowden, 2006, p.31). These inherited aspects are used as the fixed categorical limitations of the minority group as a delineation of Albino Identity by the group mind.

Archetypes are old, traditional representations that "...are part of the collective unconscious and they emerge in the individual psyche...we do not generate our own thoughts-they have an external reality of their own..." (Snowden, 2006, p.37). Blakenberg (2000) and Ngidi (2005) wrote of the meaning that others add to their physical appearance through myths. Their physical appearances could represent healer, blessings, good luck or being magically cursed (Blakenberg, 2000). These are archetypes from the collective unconscious. Turning to traditional archetypes when witnessing the colour of Albinism is in line with the beliefs of the social group.

Instincts and archetypes are both unconscious aspects of the group mind which reconstruct Albino Identity. "Many of the images contained in myths are what Jung called 'archetypes', which are recurring ...patterns of thinking that represent typical human experiences" (Snowden, 2006, p.31). The violation of an instinctual belief or social norm may push an individual into cognitive dissonance. Tradition can resolve this dissonance by offering a way of thinking using archetypes which are based in mythical stories. This validates the existence of the contradiction of colour that Ngidi (2005) articulated.

Behaviour and response of individuals can be guided by prejudice or adaptability.

#### **2.6.5 Albino Identity and family**

Personal identity integrated within a family structure enables the adolescent to explore the broader social identity. "It is that very sense of self, established within the family that enables adolescents to begin expanding relationships outside of it" (Kroger, 2007, p.54). Integration within a family is indicative of a secure pattern of attachment.

Attachment theory is a model explaining the bonds between children and parents that gives the child a basic sense of trust and emotional safety in social situations (Marone, 1998). Secure attachment is characterized by closeness with others and the absence of concerns of rejection. Security in childhood, is the absence of anxiety (Greenberg & Mitchell, 1983). Knauss (2007) advocates the importance of an individual's integration of the group experience thus illustrating the powerful effect that past positive or negative influence a group can have on the single person. Thus, the person's personal historical experience in a group organizes their present intra-psycho mechanism governing its organization (Knauss, 2007).

Anxious ambivalent attachment is characterized by seeking excessive closeness and were concerned with rejection. Avoidant attachment is characterized by a discomfort with closeness and difficulty depending on others (Pietromonaco and Barret, 2000). Sullivan's relational/structure model distinguishes between the need for satisfaction and the need for relatedness as a developmental tool (Allen & Fonagy, 2006). An assessment of relational behaviors with the primary caregiver can reveal an anxious or secure organizational pattern of experiences at various ages.

According to Sullivan distinguishing between anxious and secure experiences at an early age influence the development of the self-system and relations with the world (Greenberg & Mitchell, 1983). The relational process develops the self and influences observable behaviour, adaptive or maladaptive

responses and choice of communication method. Adaptability is that sense of security which facilitates learning and mastery over problems when the parent has provided a balance between protective behaviours and letting go (Marone, 1998). However, studies of personal adaptation in people with Albinism were mixed and inconclusive (Estrada-Hernandez & Harper, 2007).

Albino Identity is separated by family on the one side and the broader society on the other. "Personal identity divides up the individual's world of others for him. The division is first between the knowing and the unknowing. The knowing are individuals that have personal identification of the individual...The unknowing are those for whom the individual constitutes a stranger, someone of whom they have no personal biography." (Goffman, 1975, p.85). The researcher inferred that "knowing" refers to minds that exist independently of each other, yet understand and partake in a perspective and worldview that is not part of the collective unconscious. Foulkes (as cited in Nitzgen, 2011) supported the concept of 'knowing' amongst group members but described it as "unconscious instinctive understanding" (p.14). Thus, Albino Group Identity would be that shared understanding amongst the participants that result in a self-categorization with other Albinos.

Although this study will be exploring Albino Group Identity amongst teenagers with Albinism, the sharing of an identity is not exclusive to the participants. Blakenberg (2000) points out that family and parents can either share or reject that identity. She documented that if another Albino is already born into the family there is an absence of fear because "...they are used to it" (Blakenberg, 2000, pp.20). This means that the family with other Albino family members would be "knowing" already and would have shared in the social identity development of Albino Identity (Goffman, 1975). The 'unknowing' would be strangers to the research participants and to the disorder of Albinism within the broader society. The researcher has defined the 'unknowing' as those who have no personal history with Albinos. The 'unknowing' individual will be considered to be the component individual or the social individual that reflects the group mind and exhibits the collective unconscious.

“One cannot underestimate the power of family and community in providing the framework of association for those with the condition of Albinism...the acceptance of Albinos is highly mediated by the surrounding community and family” (Blakenberg, 2000, pp.20). Blakenberg (2000) further unpacks the influence of that community and family acceptance has on the primary caregiver. It is easier for the mother who bore an Albino child if there has been another Albino child in the family because the mother has more support from family members (Blakenberg, 2000). Having a previous Albino in the family will reduce the fear in the mother and family which a research participant described as “fear because it’s a different colour” (Blakenberg, 2000, pp.20). Perception of fear leads to defensive action (Freud, 1939). The fear evoked by Albinism is attributed to anxiety in the personal unconscious which leads to behavioural compensation that is aimed at increasing feelings of security (Greenberg & Mitchell, 1983). Parents can compensate for their anxiety by being overprotective as a defensive behaviour. Participants in Blakenberg’s (2000) study perceived their families to have a greater level of protectiveness over them.

Albinism destabilize traditional beliefs and judgements of the collective unconscious through non-conformity. Thus, new beliefs have to be formulated as a replacement. Parents and family members will seek validation of new beliefs through their communication with others. This might lead to what Ngidi (2005) referred to as comparisons. Social comparisons facilitate the justification of new beliefs and consolidate a coherent family sentiment. “The development of a family sentiment, is essential for the development ...of...all group feeling and action” (McDougall, 1921, p.165). Family sentiment is a show of acceptance of Albinism with a coherent, yet, altered value system that is different from the mainstream group mind. A belief system based in Albinism is reconstructed and integrated as a shared Albino Identity.

Parents with Albino children are aware of the difference of their children. Ngidi (2005) relates the story of his mother’s childhood friend, Pinky, who had Albinism. Throughout the schooling years she related the hardships she observed Pinky endure through ridicule and taunts. She was Pinky’s only

friend. In his story he continues to say that when he was born with Albinism his mother's lifelong friendship with Pinky became invaluable and he knew that he was loved and accepted. "Parents, knowing of their child's stigmatic condition, may encapsulate him with domestic acceptance and ignorance about what he will have to become. When he ventures outdoors he does so, therefore, as an unwitting passer...At this point his parents are faced with a basic dilemma..." (Goffman, 1975, p.113). Albinism makes going outdoors into the sun difficult because the lack of melanin in the skin offers little protection against the harshness of sunlight. The researcher believes that "venturing outdoors" was intended to mean 'going into society' as opposed to going into the sun. Goffman (1975) refers to the outdoors as the social aspect of 'opening' the person to others who may not accept her thus exposing the child to the possibility of stigmatisation. The dilemma that Goffman (1975) refers to, is the need of the parent to protect the child vs the social need that the child has to be outdoors and sociable. Parents are affected because they are worried that their child will be ostracised. "Ironically, worry is a way of reducing cognitive dissonance" (Slater, 2004, p.130). The presence of cognitive dissonance in the parents of Albinos, implies that they share a collective unconscious with the broader society. Parents have been pushed into cognitive dissonance due to Albinism. The protective parenting role causes a cognitive shift that is based in Albinism, reconfiguring a perspective for the parent that is different from the shared collective unconscious in their community, but still founded in Albinism, causing a dilemma for the parent.

Goffman (1975) also believes that parents make an asserted effort to compensate for their child 'default' because they are aware of the non-conformity more so than the child. Awareness of the child's stigmatic condition can cause anxiety in the parents because "...it is knowledge which inspires fear because it reveals the danger sooner..." (Freud, 1939, p.608). The anticipation of harm to the child either by exposure to the sun or social infliction is problematic for the parent of the Albino child. In Blakenberg's (2000) study it was found that Albinos thought that their parents were too overprotective towards them because of their Albinism. The condition of Albinism in a child affects the behaviour of the parent and redefines the



parenting role. Parenting is reconstituted to incorporate Albino Identity because of a shared courtesy stigma. "...the individual with a courtesy stigma (e.g. a non-Albino with an Albino sibling) may find that he must suffer many of the standard deprivations of his courtesy group ..." (Goffman, 1975, p.44). The deprivations of social acceptance and exclusion from a social group are some of the aspects that the parent shares with the child. Other criteria of stigmatisation which are part of the collective unconscious can also be met. Therefore, the parent's personal identity is shaped by the collective unconscious in the same way that the Albino child's identity is moulded in Albinism.

The partaking of parents and family members in the Albino Identity of the child is not only based in stigma. Families, generally, have their own dynamic and interaction. The parent that wishes to engulf the Albino in social acceptance can succeed. The quality of social bonds within the family is based in the verbal and non-verbal communication within that group. An Albino can be accepted or rejected by their family because of Albinism (Blakenberg, 2000). Durkheim's theory of social solidarity (as cited in Scheff, 2007) utilizes opposing indicators of pride vs. shame to assess the nature of social relationships. Exuding emotional pride is characteristic of a secure bond whereas shame indicates an alienated threatened relation despite the subtlety of non-verbal signals. Alienation has been subdivided into two forms namely isolation and engulfment (Scheff, 2007). "The idea of engulfment is centrally important to family systems theory but is rare elsewhere in human sciences" (Scheff, 2007, p.582). The role of the family in sharing the Albino Identity of the child is important in the acceptance or rejection of the child with Albinism. Albinos strive for acceptance and tolerance from family members, the community and partners (Blakenberg, 2000).

## **2.7 ALBINO GROUP IDENTITY**

The intent to explore Albino Group Identity implies that a group identity exists that can be explored. These similarities amongst participants should encapsulate a unique sameness specific to Albinism. Shared commonalities must extend beyond the diagnosis to impact of the social identity of each

participant as described by Blakenberg (2000). No research on Albino Group Identity was found by the researcher. Thus, for the purposes of this study Albino Group Identity will be defined by the researcher as a collective identity that incorporates both social and personal identities of the participants that is based in Albinism.

For Albino Group Identity to exist as a viable group identity several criteria must be met as follows (Badad et al., 1983):

1. The boundaries of Albino Group Identity must be clearly recognisable.
2. There must be a clear and distinguished out-group and in-group that can be separated based on Albinism.
3. Membership to the group must be based on an exclusive social identity that is created by Albinism.
4. A struggle with an observable group must be apparent resulting from Albinism.

In this literature review evidence has been presented that Albino Group Identity should exist. The literature reveals that the criteria that separates Albino Identity from the widespread social identity has been experienced by many people with Albinism. Evidence that the criteria necessary to create a group identity seated in Albinism will be met has been presented in this literature review. Therefore, the assumption that a group identity exists amongst teenaged girls with Albinism is reasonable. This study intends exploring the personal identity amongst teenaged girls with Albinism in order to find out if a group identity exists that is based in Albinism.

## **CHAPTER 3: METHODOLOGY**

### **3.1 INTRODUCTION**

This chapter will discuss the research methodology used in this study to meet the four objectives. This includes research design, data collection, sampling and sampling methods and data analysis.

The aim of this study is to explore if Albino Identity exists as a group identity amongst a group of teenaged girls. A qualitative research design was used to broadly understand the entirety of the group identity amongst teenaged girls with Albinism (Brink et al. 2012). Three focus groups was used to achieve this aim.

### **3.2 RESEARCH DESIGN**

Mouton (2006) ascertains the importance that research methodology must relate specifically to research goals. An exploratory research study design will achieve the research goal and objectives. Qualitative research, essentially lends itself to understanding the participants. The primary purpose for using qualitative research is to allow the researcher to:

- Study real life situations
- Explore meaning
- Gain depth in understanding human experiences
- Explore the experiences as perceived by the participants
- To ask in-depth question
- Allows participants to share experiences
- Facilitates interaction between participants

The researcher chose this approach in order to explore the lived experiences of participants who live with Albinism. This research intends to explore the personal reality and group identity of teenage girls with Albinism within a social group. The researcher will understand the personal reality of the participants by gaining insights into how the participants deal with Albinism in day to day life and which aspects of daily living is most difficult i.e. are the physical aspects of living with Albinism more difficult than social ostracism.

Group identity relates to how the social group has impacted on the participants social behaviour and outlook.

The researcher chose focus groups as the qualitative data gathering tool. Focus group research is a common research method that involves a group discussion of a specific topic that is guided by a facilitator. Thus, the group discussion will concentrate on the participant's daily, lived experience. Focus groups allowed respondents share their experiences simultaneously. They can support what the others say in their own words and reflected the personal perspective and context of the focus group participants (Bickman & Rog, 1998). Participants can share their thoughts with each other which could lead to new ideas that each participant can consider before answering. Focus groups allow the researcher to explore well framed research questions within a group context which is more efficient than in depth interviews (Bickman & Rog, 1998). This is a feasible method because the primary purpose of a focus group is to collect in-depth data about a specific topic.

### **3.3 RESEARCH PROCEDURE**

The following procedure was followed to enable the study to take place:

- Female learners in high school at a special school in KwaZulu-Natal were consulted about the idea of exploring Albinism through group interviews with the intention of educating people on what it is like to live with Albinism. Most learners supported the idea.
- A screening was conducted by the researcher at the school to determine if there are sufficient teenage girls with Albinism who meet the inclusion criteria to compose focus groups
- The research proposal was drafted and submitted to the School of Occupational Therapy at the University of KwaZulu-Natal for approval (see Appendix A, p148).
- The research proposal was then submitted to the ethics department of UZKN for approval.

- Once ethical clearance was obtained (see Appendix B, p149) permission to conduct the study was sought from the gatekeeper.
- The school principal was approached for permission to conduct the research study with high school learners (see Appendix C, p150).
- Consent forms were sent to parents for the girls to participate in this study as all the girls were under the age of 18 (see Appendix D, p151).
- As predicted by the principal, none of the learner's parents returned the consent forms. All the participants were hostel learners and under the guardianship of the principal, as is school policy (see Appendix E, p152), who granted blanket consent for learners to participate in the research (see Appendix F, p153).
- Assent was sought from the girls who agreed to participate in this study (see Appendix G, p154).
- Three focus groups were organised at the school during pastoral care of learners. A convenient time was arranged in consultation with the teachers and senior management staff to minimize the impact on the academic schedule. The researcher ran all the focus groups.
- Focus groups were conducted according to a question schedule (see Appendix H, p 155). Learners were given information leaflets prior to commencing the focus groups (see Appendix I, p156).
- Each focus group comprised four people. All the focus groups were audio recorded. The audio recording was transcribed for analysis.
- Thematic Analysis was used to analyse data. The data was then categorised and coded according to themes that emerged. Data was analysed and written into a dissertation with recommendations.
- The dissertation was submitted for grading at the University of KwaZulu-Natal
- Information will be disseminated through academic channels like the library at the University of KwaZulu-Natal and possibly through a journal article.

### 3.4 STUDY AREA

This study was conducted at a special school in KwaZulu-Natal in South Africa. The special school has grades from R to grade 12. The academic curriculum follows the mainstream academic curriculum and all subjects are taught in English. This assures a proficiency in English of learners that may be first language Zulu speaking.

### 3.5 STUDY POPULATION

The study population included 212 learners at Arthur Blaxall School for the blind. Learners presented with varying degrees of blindness due to various pathologies or physical injury. This study required teenaged girls with the specific medical condition of Albinism. It was not feasible to interview all the learners with Albinism at the special school as there are some females that are over 19 years old.

### 3.6 STUDY SAMPLE AND SAMPLING METHODS

Purposive selection technique was used to select group members for the focus group due to the rare nature of Albinism. This is a non-probability technique and is necessary as candidates are specifically selected for the purpose of the study. For the purposes of this study teenaged girls with Albinism were approached for participation. Three focus groups with four girls in each group sufficed to yield data saturation. Biographical details of the participants in the focus groups are listed in table 1.

Table 1: Biographical summary of participants

FOCUS GROUP 1	Age	Gender	Grade
Participant 1	17y 11m	Female	12
Participant 2	17y 0m	Female	12
Participant 3	17y 7m	Female	12
Participant 4	17y 6m	Female	11
FOCUS GROUP 2			
Participant 5	17y 10m	Female	11

Participant 6	17y 6m	Female	11
Participant 7	17y 9m	Female	11
Participant 8	17y 4m	Female	11
FOCUS GROUP 3			
Participant 9	17y 2m	Female	10
Participant 10	17y 10m	Female	10
Participant 11	17y 2m	Female	10
Participant 12	16y 1m	Female	10

The sampling frame was needed to ensure an adequate number of candidates are available to the researcher due to the rare nature of Albinism. At the time of the study there were 18 female learners in the high school with Albinism. Two learners were over 19 years old. These candidates were listed and twelve appropriate candidates were selected for the focus group according to the selection criteria. All the participants were teenaged females in high school. The participants all came from Zulu backgrounds but had a high proficiency in English as a second language.

### **3.7 INCLUSION / EXCLUSION CRITERIA**

The following inclusion criteria was applied:

- a. The learner must have the medical condition Albinism.
- b. An academic pass in English. This would indicate that the learner is able to adequately express herself in English.
- c. She has to be a registered learner at Arthur Blaxall School for the blind in the academic high school stream.
- d. Parent/guardian consent has been granted for participation in the study and for the discussion to be recorded.

The following exclusion criteria was applied:

- a. No parental/guardian consent given or learner assent withheld.
- b. Anti-social behaviour patterns or criminal record will be excluded to limit group processes that undermine the focus groups.

- c. Cognitive or hearing impairment as a result of any dual diagnosis e.g. TB Meningitis will be excluded because these learners are anticipated to be disruptive in group situations.

### **3.8 DATA COLLECTION METHODS**

Focus groups were used as the data collection tool. Focus group are interviews with a group of people (Brink et al., 2012). This method was chosen by the researcher because it yields in-depth data from the perspective of the participant's world view. Focus groups can explore opinions, experiences and attitudes of the participants (Brink et al., 2012). Focus group questions (see Appendix H, p155) were used to guide the discussion. The questions surrounded themes that related to the objectives of this study. Focus group questions informed the study of the psycho-social reality of Albino Identity as a shared group identity and the shared social experiences and the common social constructs in living with Albinism. The focus group question was review and approved by a research supervisor at the University of KwaZulu-Natal. The focus group questions were piloted on older high school learners who did not participate in the study. Learners gave the researcher feedback on how to improve the question schedule which was amended accordingly.

### **3.9 DATA COLLECTION PROCEDURE**

The focus group procedure was the same for each focus group. The participants arrived in the Occupational Therapists office which had been set up for the focus groups. The participants entered the room together. On entering the office, the researcher gave the participants information sheets (see Appendix I, p156) and assent forms (see Appendix G, p154). The participants sat on the chairs that had been set out and read through the information sheets and assent forms. The researcher checked for understanding and asked if clarity was needed on any points. Satisfied with the information sheets, participants signed the assent forms prior to commencing the focus group. The audio recorder was placed in the middle of the group and the researcher then commenced the focus group by reading the information sheet out to each focus group to ensure clarity. The



researcher then requested that participants not to use names to maintain confidentiality because the group was being recorded. The questions were accurately asked according to the focus group schedule (see Appendix H, p155). Spontaneous interaction between the participants, like mild disagreements and agreements, were allowed during the course of the focus groups. The participants never went off topic. Audio recordings were transcribed into written words for accurate documentation. This allowed the researcher the flexibility to review the data repeatedly for detailed analysis.

The focus group was facilitated by the researcher who is employed at the school because all the learners expressed distrust of speaking to any new individual during the pilot study. The researcher does not have Albinism and was the only non-Albino in the group.

### **3.10 DATA MANAGEMENT**

Material and its transcriptions was stored in a locked cupboard. All the records will be deleted after 5 years and transcriptions will be shredded to maintain anonymity. The school was acknowledged in the research for its immense support of the research process.

### **3.11 DATA ANALYSIS**

The data analysis was divided into four stages. The first stage of the data analysis was transcribing the audio recordings into written transcripts. Transcription was accurate.

The second stage of the analysis consisted of the reading and re-reading of the three transcripts. During the first analysis, key phrases were identified into sub-themes. The researcher used eleven coloured tabs to highlight the same ideas that emerged from the text along concepts of social unconscious, the mind, the self, belonging etc. Categories were then re-read and recurring words were identified. These key words were then coded into emerging themes. The themes emerged from the personal accounts of the participants. The analysis of data according to themes is referred to as Thematic Analysis (Mouton, 2006).

These emergent themes were then regrouped into broader categories according to the aim of the study in the third stage of analysis. These categories were relevant to all three focus groups. The pertinence of each category was ensured by sourcing evidence in the literature review. The focus groups allowed the researcher to add layers of meaning to better understand the participant's perspective.

The fourth and final stage of analysis was a consultation with the researcher's supervisor to ensure that the analysis was accurate and reasoned in a logical method.

The focus group questions were used to direct the process of data analysis. The questions were designed to yield information regarding a number of aspects of Albino Identity from the focus groups.

### **3.12 TRUSTWORTHINESS**

Trustworthiness is the authentication of qualitative research procedures to ensure the credibility and accuracy of the research findings (Brink et al. 2012). Brink et al. (2012) explains that confirmability, dependability and transferability improves trustworthiness. Confirmability is the confirmation of the accuracy and meaning of data (Brink et al. 2012).

In this study confirmability was ensured through purposive sampling and data saturation. Purposive sampling guaranteed that teenagers with Albinism were engaged in order to inform the aim of the study. Data saturation was ensured through the use of three focus groups.

Participants displayed enthusiasm in sharing their lived experiences. This enabled the researcher to elicit relevant rich data voluntarily. The disagreements and agreements that was freely displayed in the group is an indication of the authenticity of responses from the participants and improves trustworthiness of the study (Kidd & Parshall, 2000). Reflexivity between facilitator and participants during the focus group discussions was important

to ensure trustworthiness because issues raised by the candidates were explored to eliminate ambiguity.

Trustworthiness in focus groups is improved by the depth of analysis of data (Kidd & Parshall, 2000). Focus group questions were piloted to ensure that they were phrased accurately to eliminate ambiguity and obtain relevant data for the study. Researcher bias was limited by providing a specific set of questions with probes which the researcher adhered to in all the focus groups. This study used thematic analysis to improve trustworthiness by ensuring that the data was correctly coded and analysed. Theories from psychoanalysis, group analysis and social construction were triangulated to determine the psycho-social group framework. Theoretical triangulation ascertained credibility of analysis.

### **3.13 ETHICAL CONSIDERATIONS**

The research protocol for this research was submitted to the ethics committee of the school of Occupational Therapy at University of KwaZulu-Natal. It was reviewed under the guidance of Prof Heerden and approved (see Appendix A, p148). The protocol was then submitted to BRECS at the UKZN who approved the protocol (see Appendix B, p149).

Next, permission for this research was obtained from the gatekeeper. Permission was sought from parents. Information sheets (see Appendix I, p156) and permission slips were posted to the parents (see Appendix D, p151). The researcher was advised that parents were consistent in their non-response to school letters in general. None of the parents returned the consent forms. Thereafter the legal guardian, the school principal, gave blanket consent for learner participation in writing (see Appendix F, p153). The school principal is the legal guardian of all hostel learners because it is school policy that parents must transfer guardianship to the school principal during hostel registration of each school year. Guardianship of learners is transferred to the school principal via a signed Transfer of Guardianship and Indemnity form (see Appendix J, p157). The school principal was the legal

guardian of all the learners that participated in this study because all participants resided in the school boarding hostel.

Anonymity was guaranteed because no names were used during the interviews or on the transcriptions. Confidentiality was ensured by disseminating the information in academic undertakings only. Audio material was not publically broadcasted. There was no compensation nor any cost to the participants of this study. During the focus group one participant became distressed and was crying when relating painful memories from her childhood. The group became empathetic and after the research session a counselling session was arranged with the participant. She said it felt good to get support from so many people.

## **CHAPTER 4: FINDINGS**

### **4.1 INTRODUCTION**

In this section the results from the focus groups described in Chapter Three (Methodology) will be reported and interpreted according to the objectives outlined in Chapter One (Overview).

### **4.2 DEMOGRAPHIC DETAILS**

Three focus groups of four learners each were conducted at a special school in the KwaZulu-Natal Midlands, South Africa. All participants were female teenagers ranging in age from 16 to 18 years. The participants were first language Zulu speaking but attended an English medium high school catering for special needs. The participants were in grades from 9 to 12 and had passed academic examinations written in English. All the participants were boarders in the school hostel. Participants had Albinism and all had a complete lack of pigmentation in their eyes, hair and skin.

### **4.3 THEMES**

By using thematic analysis that was outlined in Chapter Three (Methodology) the main theme that emerged was the theme of difference. The theme of difference was evident. Different is the label that the social identity gives to the participants because of their Albinism. Adding personal meaning to the difference by determining whether or not the difference makes them special demonstrates the impact that the difference has had on the personal identity of the participants.

Difference is a theme prevalent in the social experiences and social interaction of the participants. The theme of difference affected how others interacted with the participants socially. Difference also influenced how the participants interacted with others in peer relationships.

Social constructs is also based in a theme of difference which informs objective three. Family, school and the social community responded to the

difference of the participants which altered social constructs. This theme of difference penetrated all areas of group identity thus creating the psycho-social constructs. Being different due to Albinism is the foundation of the group identity amongst the participants.

In this chapter, the researcher will focus on the difference as the main theme relating to Albinism and the impact that it has had in shaping the personal and group identity. The subset that has emerged from this data is outlined in Table 2 below. The subsequent reports from transcripts will number participant quotes in a numerical sequence as they are used under each heading. This assists ease of reporting and it maintains the confidentiality of the participants.

Table 2: Coding Frame

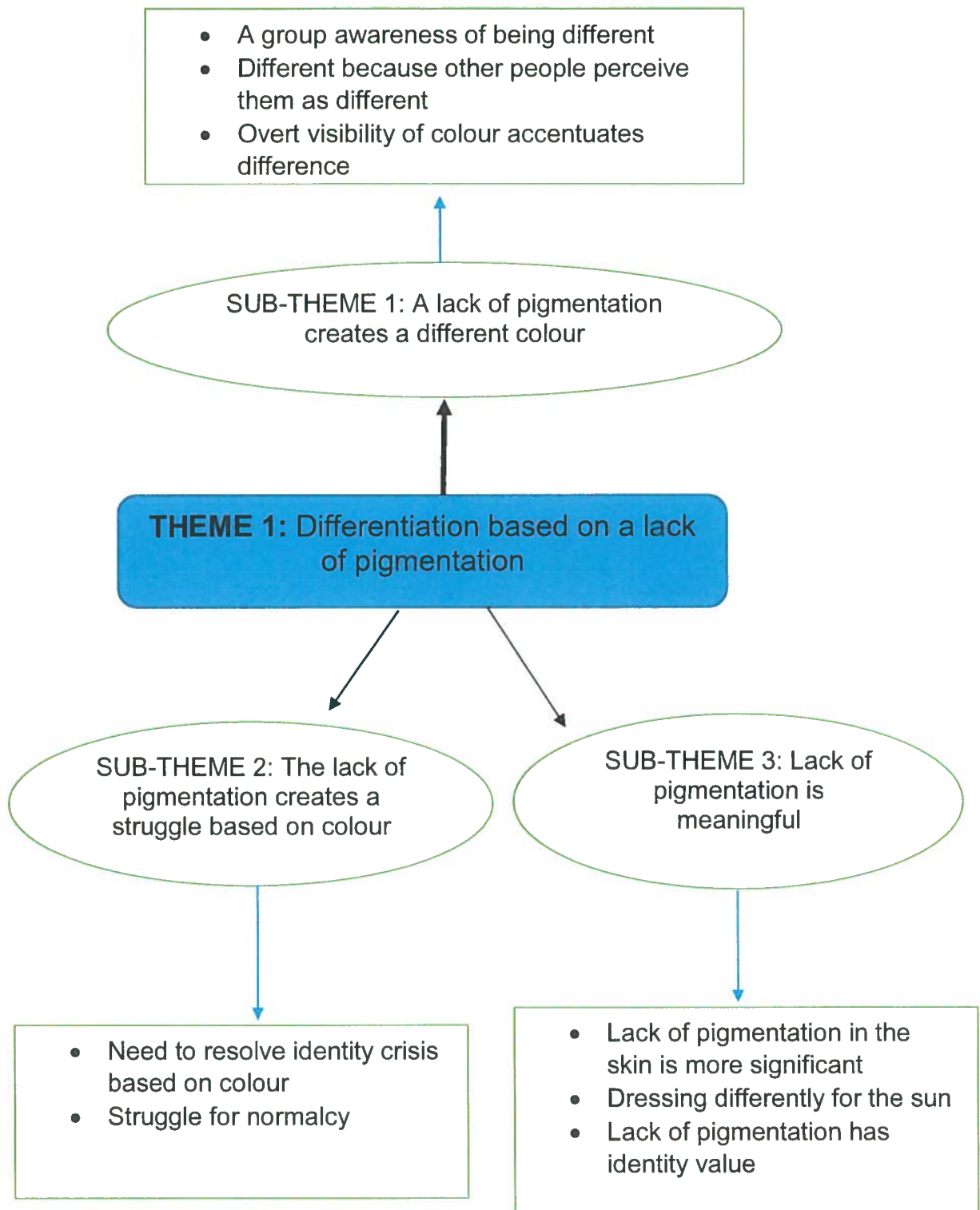
NUMBER	THEME
<b>4.4</b>	<b>THEME 1: Differentiation Based On a Lack Of Pigmentation</b>
4.4.1	Sub-theme 1: A lack of pigmentation creates a different colour
4.4.2	Sub-theme 2: The lack of pigmentation creates a struggle based in colour
4.4.3	Sub-theme 3: A lack of pigmentation is meaningful
<b>4.5</b>	<b>THEME 2: Treated Differently Because of Colour</b>
4.5.1	Sub-theme 1: Treated differently because of myths
4.5.2	Sub-theme 2: Treated differently because of colour
4.5.3	Sub-theme 3: Personal opinions
4.5.4	Sub-theme 4: Treated differently by family
<b>4.6</b>	<b>THEME 3: Albinism Changes Social Interaction</b>
4.6.1	Sub-theme 1: Social interaction with family based on the an acceptance of Albinism
4.6.2	Sub-theme 2: Social interaction with family based on the rejection of Albinism
4.6.3	Sub-theme 3: Albinism changes social interaction with peers
4.6.4	Sub-theme 4: Mainstream schooling is influenced by Albinism
4.6.5	Sub-theme 5: Social interaction at the special school where there are more Albinos

Each theme will be discussed in detail together with the sub-themes. At the beginning of each theme discussion, the researcher has compiled diagrammatic representations to clarify the relationships between themes and sub-themes.

#### **4.4 THEME 1: DIFFERENTIATION BASED ON A LACK OF PIGMENTATION**

The theme of difference due to a lack of pigmentation emerged from all three focus groups in various ways. The theme of being different due to a lack of pigmentation determines how the social identity shapes the personal identity of the participants. This theme also informs the psycho-social reality of Albino Identity as a shared group identity as outlined in Figure 1.

FIGURE 1: Theme 1 outlined according to themes, sub-themes and layers





#### **4.4.1 Sub-theme 1: A lack of pigmentation creates a different colour**

The primary theme that emerged from the focus group discussions was that society saw the participants as different due to a lack of pigmentation. This fundamental theme is also the basis for all the other subthemes that emerged according to the participant's experiences. The participants perceive that they are excluded from the broader social group. According to the participants the reason for their exclusion is based in their difference in appearances due to Albinism. Participants in the focus groups stated:

*Participant 1: "Some people don't understand us, the way we look...cos you different from them."*

*Participant 2: "...you different. My mom is brown and I am this colour."*

The separation of the participants from society has lead all the participants to refer to 'they' or 'people' whom the participants view as a separate group. These 'people' are a group that excluded the participants from having a sense of belonging. Participants used the word 'they' or 'people' as the groupal names to describe people who treated them differently because of Albinism or who believed in myths that surrounded Albinism.

Each participant believed that she was excluded from society based on the colour presented by a lack of pigmentation. The participants believed that they were different because their colour is different. A participants described being misunderstood by society because her colour is different. All the participants showed a level of accepting the label of difference that society has given them due to a lack of pigmentation. The participants show an acceptance of this segregation as a reality.

##### ***a. A group awareness of being different***

The participants all spoke their difference due to Albinism. Each participant has incorporated this difference into their identity as a participant reported:

*Participant 1: "You see yourself different from everyone."*

*Participant 2: "I'm an exception...because I'm an Albino"*

The participants all saw themselves as different from everyone in society. All participants have accepted 'being different' but had polarized perceptions of their Albinism. Participants were aware that exceptions were made for them because of their lack of pigmentation. Nobody in the focus group contested her saying that she is an exception due to her Albinism showing agreement amongst the focus groups.

#### ***b. Different because other people perceive them as different***

The main reason that the participants gave for being different from everyone is that other people can see their lack of pigmentation.

*Participant 1: "I mean we different... you not different but you different because people look at you differently..."*

All three groups that participated in the research expressed an indelible awareness of 'difference'. It is a reality for each participant and an accepted description of "us". To say "we different" indicates a unity within that difference. They share the same difference from other people. She said that she is not different from the person that she would be if she had pigmentation in her skin, hair and eyes. Yet, she says that the way that others look at her is what makes her different. People look at her differently because of her lack of pigmentation. This shows that the participants are very aware of how others perceive them. They believe that they are different because others see them as different.

#### ***c. Overt visibility of the colour accentuates difference***

Albinism changes the colour of the skin, hair and eyes of the Albino. All three aspects are visible to others who look them.

*Participant 1: "They can see that you are not a white person but you are not black like the black people".*

The skin is external. Other people can see their skin. It is this ability of others to see the colour of their skin that draw attention. The participant's reference to "not a white" has racial and cultural connotations. The other being able to see that the African Albino is 'not a white' that the participant said refers to facial features. The participants have African facial features but their skin is not the same colour as other African people which the participant refers to when she says 'not black like the black people'. Yet, the colour of the skin is the primary foundation of racial classification that the participants encounter. The participants seem to understand that the combination of African facial features and light complexion causes confusion for others who attempt to racially classify them. The participants believe that the ability of other people to see that their skin colour lacks pigmentation despite their African facial features is what changes the perception of others.

The phrase "not black like *the* black people" is an interesting use of language that separates the Albino from the entire African race. This perception of the participant shows that she views herself as not a member of the broader African community as a group. She sees herself as separate from African society due to her Albinism.

#### **4.4.2 Sub-theme 2: The lack of pigmentation creates a struggle based in colour**

In all three focus groups it emerged that the lack of pigmentation due to Albinism creates psycho-social struggles for the participants. The resolution of an identity crisis that is based on the colour created by Albinism is pertinent to all the participants. Accompanying the resolution of identity crisis is the struggle for normality.

**a.      *Need to resolve identity crisis based on colour***

Albinism changes the colour of the participants due a lack of pigmentation. This colour is then racialized and cultural meaning is added to the appearance of the participants. A black in KwaZulu-Natal is general term used to refer to a person of the Zulu culture. A white is term generally indicating a European. As found earlier in this chapter, the colour of the participants are categorized into these two contradictory categories. This contradiction has created a struggle within the participants:

*Participant 1: "Ay Mina, I'm a white, a black person living in a white person's body"*

*Participant 2: "I'm black living in in a white person's skin."*

The colour of each participant dominates the person and their state of being. Being a white person vs being a black person was an internal struggle that all the participants related.

The skin colour is particularly important in the group of participants. The skin appears light due to the lack of pigmentation which creates the 'whiteness' like the European. Yet, as each focus group progressed the 'white' colour permeated into other meanings. The 'white' skin colour became 'being white' as the participant explained when she said "I'm a white" and then she contradicts this by saying that as a person she is an African. The participants explained that their skin colour influences their definition of themselves as a person and it challenged their cultural classification of themselves. All the participants identified themselves with the African culture but that their skin colour was not consistent with the African group's skin colour.

**b.      *Struggle for normalcy***

The myths that others have about the participants have impacted on each participant. The value system that emerges from the participants in response to the myths is a group striving for normality.

*Participant 1: "I'm like any other person"*

*Participant 2: "we just like any other child..."*

*Participant 3: "God, I'm not cursed, I'm not a blessing, I'm just like every other child."*

Contending with myths regularly has meant that the participants seek normalcy. All the participants advocate their shared humanity with everyone else. The participants identify themselves as ordinary people.

**4.4.3 Sub-theme 3: A lack of pigmentation is meaningful**

The lack of pigmentation is meaningful for the participants in their daily lives beyond the social aspects. Having no skin pigmentation is more important to the participants than the lack of pigmentation in their hair and eyes. The lack of skin pigmentation requires special attention and care and makes the teenagers dress differently from their peers and family. The lack of pigmentation is an important factor to each participant to the extent that it changes the opinion that they have about themselves.

**a.      *Lack of skin pigmentation in the skin is significant***

All the discussions in the three focus groups surrounded their skin as an accentuated area that impacted most significantly on the participant's daily life. The lack of pigmentation in the skin is meaningful to the participants in various ways. The lack of pigmentation meant that the sun posed a threat to their health. Melanin in the skin offers the body protection from the sun. In

Albinism, the absence of melanin production means that the Albino is vulnerable to the harshness of the sun.

*Participant 1: "Living with Albinism is like living with any other condition, it just has different ways that you need to treat it, you can't just go into the sun, you have to use sun protection..."*

During the three focus group discussions all the groups agreed that the sun poses a problem for them and that taking precautions in the sun was important to avoid painful sunburns. All the participants in the groups could relate to each other when it came to taking precautions for the sun due to their Albinism. All the participants showed an acceptance that living with Albinism is different than living with a normally pigmented skin. Tending to the skin is an important part of their health care due to Albinism as a medical condition. All the participants mentioned it as is part of their daily self-care routine. Awareness of the harsh sun is an ingrained value system for all the participants. Protection from the sun is an important aspect of daily life for the participants due to their Albinism. This shared commonality shows a conformity amongst the group. The participant's understanding of this special adaptation to their daily life is that it is necessary due to a medical condition like every other diagnosis. None of the participants referred to the lack of pigmentation in their hair or eyes as having a significant impact on their daily life.

***b. Dressing differently for the sun***

As a self-protective action to compensate for the lack of melanin in their skin, the participants all dress similarly in the sun.

*Participant 1: "And the sun, you have to be extra careful about what you are wearing, let's say that you and your family are going to the beach, you'll see your cousins and sisters wearing shorts, you'll be wearing a loooooong pants" (everybody laughs)*

*Group: "Yes"*

Activities in the sun affect the participant's skin and they have to dress in a way that protects their skin from the sun. This affects their appearances so that they dress differently to their social group who can wear summer clothing. Thus the lack of pigmentation in the participant's skin determines the way that the participants dress in public. The participants are all teenagers and the way that the long clothing was described indicates a yearning to wear shorts and to dress like their peer group.

The beach is considered to be a fun social activity when family relax together. The sun is harsh for the participants with Albinism due to the lack of skin pigmentation. As a girl in another group reported:

*Participant 2: "You can't stay on the beach for long, you always have to wear a big hat and glasses..."*

This affects their ability to be fully immersed in outdoor group activities because they are unable to spend time in the sun. None of the participants saw this separation as a rejection and none mentioned that their Albinism prevented their family from such activities. None of the participants mentioned avoiding family activities that is outdoors. All the participants indicated that they adapted to the social activity. All the participants conformed to dressing for the sun as a precautionary part of their daily life.

**c. *Lack of pigmentation has identity value***

The way in which others treat the participants has had an impact on the way in which the participants see themselves. All participants have accepted 'being different' but had polarized perceptions of their Albinism. Some participants said that they enjoyed being different describing living with Albinism as "fabulous, unique" and "special". All these participants cited incidents of being made to feel special, being appreciated by others or making others or their family look good socially or on special occasions. As a

participant related being regularly pushed into the limelight by her church because, as she explained:

*Participant 1: "I'm an exception...because I'm an Albino and they want their whole image to shine."*

Not all the participants in the focus groups shared this viewpoint. Some participants said that they felt that their lack of pigmentation was insignificant.

*Participant 2: "I don't see myself different from others even though I'm white as my comrade has said. I just don't see myself as different because I'm like any other person. Me being in a white person's skin doesn't really make me different."*

Each participant had their personal opinion of whether the difference in their skin colour made them special or not. Participants openly challenged each other on the topic:

*Participant 3: "I was telling her that being white doesn't make you special"*

*Participant 4 responds: "It does."*

Some participants embraced and enjoyed being different and some did not think it's important. Some participants described living with Albinism as difficult:

*Participant 5: "For me living with Albinism use to be very hard because I sometimes felt like an outcast, I felt like I didn't belong."*

The participant describes that living with Albinism was difficult for her as the only Albino in her community. She identifies several reasons her lack of pigmentation made her feel different from other people. She felt like an outcast by people who had rejected her Albinism. She describes feelings of

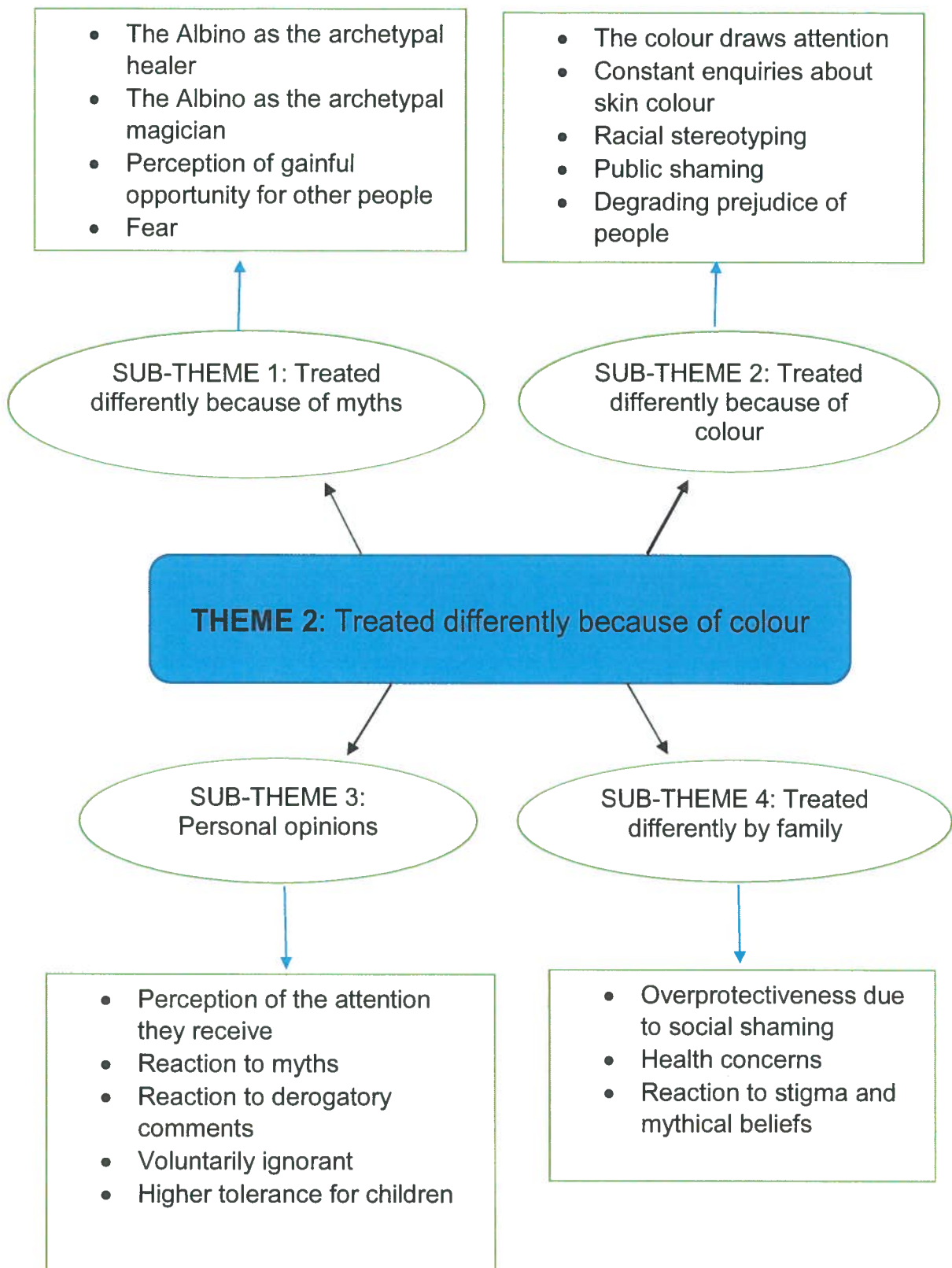


isolation because she didn't belong. It was difficult for her to cope with daily life as a solitary Albino.

#### **4.5 THEME 2: TREATED DIFFERENTLY BECAUSE OF COLOUR**

The participants related their social experiences during the focus groups. All the participants had similar experiences due to their Albinism. This emergent theme surrounding social experiences, as outlined in figure 2, contribute to the psycho-social reality of the participants.

FIGURE 2: Theme 2 outlined according to sub-themes and layers



The second theme that emerged from the focus groups is that Albinism changed the manner in which the participants were treated. The theme that emerged from the focus groups was the different ways that other people treated the participants:

*Participant 1: "They look at you differently and treat you differently because you are Albino"*

*Participant 2: "people treat you like you are something else"*

The participants identified the reason that people treated them differently was because of their Albinism. Being an Albino meant that others looked at them differently and treated them differently than they would normally pigmented peers or family.

#### **4.5.1 Sub-theme 1: Treated differently because of myths**

Myths are stories that are based around archetypes. Through narrating fables around these archetypes myths serve to explain unusual phenomenon. The participants have all experienced myths which others imposed onto them. Myths surrounding Albinism either exalt or degrade the Albino. Exaltations or degradations vary depending on the person with whom they are interacting. In both respects the Albino is being regarded as separate from the human race which undermines the humanity of the person with Albinism as can be seen in the following quote:

*Participant 1: "some people will go to the extent of asking you do you disappear when you die and where do you disappear to"*

Questions surrounding the mortality of Albinos exemplifies the Albino from entitlement to a human death, common and shared between humans. Disappearances replace the process of dying, excluding Albino from a human death that allows them entry into paradise or the punishment of the grave.

Additional myths portray the Albino has possessing special powers or embodying healing powers. Variations of myths circumvent two archetypes namely healer and magician.

**a.      *The Albino as the archetypal healer***

The archetypal healer possesses magical healing powers that can cure the sick and rejuvenate wellbeing. The participants in the three focus groups have all encountered people who believe that Albinos can heal mystically. Myths include the embodiment of blessings and good luck and possessing the ability to heal others.

*Participant 1: "People believe that if you an Albino you have special powers and you can heal HIV or you a blessing to the family"*

The participants reported that people perceive that the Albino possesses special powers and are able to convey approbations. Divine power is bestowed onto the participants. The participants were aware of this as one participant said:

*Participant 2: "Like we God and we can bless the people one way" (group laughs)*

The participants were aware that the myths conferred superhuman healing powers onto them. Here the participant noted that these supernatural powers are actually a comparison between the Albino and a Higher Being. The group laughed at the comparison of the Albino to a Higher Being because they found the comparison amusing. The comparison excludes the participants from religion where they can be governed by a God.

**b.      *The Albino as the archetypal magician***

The archetypal magician possesses supernatural powers to appear, disappear or simply the incarnation of divine punishment or curse. All the

participants in the focus groups have been exposed to others who believed that Albinos possessed magical powers because of their colour:

*Participant 1: "...When Albinos die they disappear, their blood is not red, its blue, Albinos came from the sea and it's a curse when you have an Albino child. It's because you have laughed or teased an Albino before that's why God is punishing you with an Albino child..."*

Myths that surround Albinism as the archetypal magician state that Albinos are primarily not from human origins but that they came from the sea. These myths deny the Albino a human birth or little commonalities of humanity like a shared blood colour.

Other myths justify the birth of an Albino stating that the reason an Albino is born is because of divine wrath such a magical curse or divine punishment of the parent who bore the Albino child. Myths that draw speculation of the colour of the Albino's blood is blue which separates the Albino from the rest of humanity.

### ***c. Perception of gainful opportunity for other people***

The participants reported that the behaviour of others change because they want to gain from their Albinism by giving them money or trying to benefit from them in some way.

*Participant 1: "...I've had community members giving me money saying that I must pray for them cos they want to be lucky"*

*Participant 2: "And people give you money...because they think that they going to get more and more."*

The participants explain that others change their behaviour to try and take advantage of them for personal benefit. The participants describe how others have objectified them in order to gain from them. People want to capitalize

from their perception of Albinism. Some people believe that they will get an increased amount of money or have more luck by giving an Albino money. The participants understand that others see a gainful opportunity in contact with an Albino. Participants in all the focus groups have received money from strangers because of their Albinism.

All the participants have reported experiencing an invasion of their personal space by strangers who hope to gain from them. The violation of privacy usually presents as people wanting to touch them. People disregard the participant's personal space by randomly approaching them. Yet, all the participants report that they are regularly approached by strangers who invade their personal space and violate their privacy because of a belief in myths that surround Albinism.

*Participant 3: "...and then you have this person that will come up to you, they want to touch you and they believe that they will have good luck..."*

*Participant 4: "...they also believe that if they touch you, they get blessings"*

The participants identified the main reason that others violate their privacy and invade their personal space is because the other is motivated by a false belief. Believing that Albinism is associated with blessings and good luck changes the behaviour of people who hope to gain from the participant's Albinism. They believe that by touching the Albino that good luck and blessings will be transferred onto them. Essentially, the violation of privacy and the intrusion of others onto the personal space of the participants is seated in Albinism. None of the participants reported that they refuse to let strangers touch them.

#### **d. Fear**

The participants described that people were scared of the colour presented by the Albinism and adapted their behaviour according to their fears.

*Participant 1: "... then in some instances people not touching you cos they feel you going to rub on the colour and they feel when you touch an Albino you turn into one."*

Participants in all the focus groups have encountered people who did not want to touch them because of the Albinism. This overt avoidance of the Albino signifies a defensive action of the other based on a fear of the colour due to a lack of pigmentation. Some people did not understand the lack of pigmentation and feared that the colour was contagious and they could contract Albinism via touch. They believe that they will lose their pigmentation and become an Albino through physical contact with an Albino. They, therefore, adjust their behaviour toward Albino, behaving fearfully to avoid a perceived threat.

#### **4.5.2 Sub-theme 2: Treated differently because of colour**

The participants were aware of being different. Yet, it is this difference that was identified as the reason that people treated the participants differently. Participants recognised several patterns of behaviour in people who reacted to the difference of the lack of pigmentation:

- Difference draws the attention of strangers
- Constant enquiries or discussions about aspects of Albinism
- People racially stereotyped the participants
- People publically shame the participants
- People react with prejudice

##### **a. *The colour draws the attention***

The drawing of attention from the others is a common theme that emerged in all the focus groups.

*Participant 1: "You draw attention."*

The participants saw themselves as responsible for capturing the attention of others. All the participants acknowledged that they, as a group, are the source of drawing the attention of others. None of the participants said that others are responsible for voluntarily directing attention towards them. The girls explained that in public their appearances drew the attention of strangers.

*Participant 2: "When you walk in town, or a public place people will be staring at you..."*

*Participant 3: "People stare at you..."*

All the groups said that strangers will stare at them when in public. Anonymity in public or social situation is absent for the participants. If they do not want attention then they are confined to their home. The drawing of attention of strangers emphasizes the outward difference of the participants. None of the participants reported that they blended into the background in public or social situations.

#### **b. Constant enquiries about skin colour**

After people have approached the participants, the content of the ensuing discussions is the same for all the participants. The participants reported that the content of the communication of the other with the participants always surrounds Albinism in various ways. Either the participants are spoken to about aspects of Albinism like the lack of pigmentation and oculomotor dysfunction, or the myths that surround Albinism. Often the participants are spoken to with prejudice or they are stereotyped into a category.

Aspects of Albinism that the participants are frequently asked about are specifically related to their lack of skin pigmentation and eye movements.

*Participant 1: "...lots of questions... then they ask why you this colour and your mother is this colour, they ask what's happening."*



In all the focus group discussions the girls described people asking about their skin colour. Strangers point out the difference in skin colour between the participants and their parents and demand an explanation from the participants. The content of the enquiry of other people was always around appearances and people always tried to understand their lack of skin pigmentation. None of the participants reported that others made enquiry about their blond hair or green/blue eyes.

### **c.     *Racial stereotyping***

Other people add a stereotypical label to the participants which is a classification of the participants. The participants reported that they were often incorrectly stereotyped into a racial category by others who randomly approached them. Their racial classification was based entirely on their appearances due to their lack of pigmentation:

*Participant 1: "And when they greet you they greet you in English, they think you are a white."*

The manner in which other people treat the participants altered according to a stereotype. A change in the use of language such as English instead of Zulu indicates the mind-set of the other towards the participants. The participant's lack of pigmentation is interpreted by the other to be specific to the English culture showing an exclusion of the participants from the African race. The other adds meaning to what they perceive as a difference in appearance of the participants.

### **d.     *Public shaming***

In all the focus groups it was reported that there was a notable shift in the non-verbal behaviour of people which the participants attributed to their lack of pigmentation.

*Participant 1: "...they stare at you and laugh and point fingers at you...because you are different from them"*

*Participant 2: "Little children will stare at you and ask "what's wrong with you"... and sometimes even old people."*

*Participant 3: "Yes, and they'll take photographs."*

All the participants reported that in public situations strangers would treat them differently. Other people would gesture towards them, pointing and laughing or taking photographs of them. Children and old people ask questions without restraint. These actions are rude and can cause embarrassment for the participants. This non-verbal communication constitutes public shaming of the participants by other people.

#### ***e. Degrading prejudice of people***

Prejudice involves the degradation of one by another. All the participants reported that they had experienced discriminatory language by strangers who always refer to the colour of their skin that has been altered by Albinism.

*Participant 1: "Ay, sometimes, where I live, the people around me, the community, they used to tease me and call me bad names."*

*Participant 2: "They say 'mlungi'"*

*Participant 3: "Hmmm, Ya, like being white, things like 'eshowa'"*

*Participant 4: "They even compare us to Coloureds"*

Other people react to the colour of the participant's skin by giving them derogatory labels. Strangers verbally categorise the participants into a group that is labelled 'mlungi' or the degrading category of 'eshowa'. This alteration in communication by the other is a direct result of the participants Albinism. All

the participants have experienced this prejudice from a young age. Despite living in the same community for a long time. A teenager that has lived in the same community her entire life describes how other people in her community still calls her derogatory names because of her Albinism.

#### **4.5.3 Sub-theme 3: Personal opinions**

The participants have all reported that others treat them differently because of their Albinism. They have all been made to feel special or encountered prejudice, racial stereotyping, myths and a disregard for their personal space. Each participant had a different perception and reaction to the way others treated them. The participant's perceptions that emerged from the group discussions can be grouped into broad categories:

- Perception of the attention that they receive
- Reaction to myths
- Reaction to derogatory comments
- Voluntary ignorance
- Higher tolerance for children

##### ***a. Perception of the attention they receive***

The participants each had an opinion of the way others reacted to them when they are in public:

*Participant 1: "I like the attention"*

*Participant 2: "I don't like the attention...people should just stop giving me the attention..."*

*Participant 3: "I don't have a problem (with the attention)"*

The reaction of the participants to the behaviour of others varied widely from enjoying the attention to indifference or not enjoying the attention. The reaction of the participant was dependant on the individuality of the

participant. Although others treated each participant the same, the participant's perception of that behaviour differed. Many of the participants focused on the compliments they received due to their lack of pigmentation. As one participant said:

*Participants 4: "And we get compliments, beautiful compliments..."*

Participants reported that they enjoyed the positive attention that they received based on their lack of pigmentation. Participants described "nice" people who made them feel "special". All the participants accepted the compliments of others as authentic. None of the participants in the group discussions expressed any repulsion to receiving compliments around their lack of pigmentation.

#### **b. Reaction to myths**

All the participants in the three focus groups have encountered the mythical beliefs that others have about Albinism. This had meaning to the all the participants and they each had an opinion on this issue because it was a feature in their lives. The participants themselves do not subscribe to myths surrounding Albinism.

*Participant 1: "Culturally they say it's a blessing, for me I think I don't agree."*

*Participant 2: "Even those living in rural areas, they know we not a curse and neither are we a blessing"*

Even though none of the participants prescribed to myths that surround Albinism, all the participants had incorporated opinions that arise from the mythical belief of others as a value system. The reaction of individual participants varied greatly. The participants expressed a variety of emotions when continuously dealing with others who believe in the myths. Some participants reacted with frustration to constant enquiries around the myths associated with Albinism.

*Participant 3: "When they say 'is your blood blue' I just say 'yes, it's blue if you feel like its blue' cos I feel like it's stupid to say so...and they ask where do we disappear to? Like really! Disappear!"*

All the participants expressed a rejection of the myths that they continuously encountered. One participant expressed an unrelenting frustration with having to deal with myths all the time, describing it as foolish. They dismiss the myths that separates them from basic humanity because the participants do not correlate themselves to any deity. This understanding is the foundation of their rejection of all myths. The participants have encountered others who will try to take advantage of them because of a belief in the myths that surround Albinism. The participants described being offended by those who want to use them for personal gains.

*Participant 4: "I don't know how old I was and a lady was selling fruit, she was like I must touch her fruit so she gets luck and people will buy her fruit... but when it comes to touching of the fruit, it's kind of offensive."*

The embodiment of myths has been a lifelong awareness for the participants and has started at a young age. Others have tried to use the participants for their own benefit, like asking a child to touch her fruit so that she can sell more fruit.

The participants said she was offended by the behaviour of the stranger indicating that she perceived the behaviour of the woman to be disrespectful. The participant instinctively knew that this was wrong despite being too young to articulate that it was a violation of social rules. The participant never said that she tried to rectify the woman's behaviour leading to the conclusion that the participant was quietly irate at the offense.

A participant who believed that people are resistant to learning about Albinism amused that she accepts any payment offered to her because of Albinism and that she enjoys spending the money that others gave her.

*Participant 5: "When it comes to money you must take the money and spend it...It's their loss, they didn't want to go and learn about Albinos so why not spend the money."*

Participants in the focus groups put the onus of understanding Albinism onto the people in society saying that they should have made the effort to educate themselves about Albinos. She realized that those who are educated about Albinism would not give her money and that through education and understanding of Albinism the behaviour of the other would change.

At no point did she say that she would go and advocate for payment or try to manipulate others in order to convince people to give her money. At no point did she say that she would assure the others that she would pray for them or that the money would bring them luck. She never indicated that she misled anyone. Her attitude is that the money is offered to her because others do not want to know about the medical condition. The belief that Albinos are good luck is so strong that people would give money to the girls believing that they would get more in return. Refusing to accept the money would undermine the other and would have consequences for her, so she might as well enjoy spending it. Some participants expressed annoyance:

*Participant 6: "Especially old men, they like Albinos \*group laughs\* serious, and they give me some money, it's so irritating. Ay!"*

This participant expresses irritation at old men who offer her money. The participant's use of the plural word 'men' implies that she is referring to more than one incident. This constant social harassment is bothersome to the participant. The participant perceives the behaviour of old men to be disparaging and reacts riley to the social manipulation.

Some participants were completely indifferent towards the myths that they encountered.

*Participant 7: "I don't feel nothing because I don't believe all of that... I know it's not true."*

*Participant 8: "Me too Mam, I don't feel anything."*

The indifference that the participants had towards the myths that others held about their lack of pigmentation shows that what others believe is not important to the participants. They indicate that it does not affect them and in no way is it a reflection of the person that they are.

### **c.     *Reaction to derogatory comments***

The belief of others in the myths that surrounds Albinism engulfs the other to the point that they would cross reasonable personal space of the participants. Invasions on the participant's personal space include verbal communications and physically touching them.

Many participants reacted in different ways when enquiries are made about their lack of pigmentation. Although the other will sometimes use degrading language or ask personal questions the participants describe the continuous effort that they make to try to control themselves.

*Participant 1: "...So for me...I try as hard as I can not to be rude and to just ignore those comments..."*

*Participant 2: "At first I felt sad but now, they still call me bad names but I just let it go away...When I was a child I felt discriminated against but now that I've grown I don't have a problem."*

*Participant 3: "I just ignore them"*

A participant elaborated on the difficulty she had in dealing with derogatory names when she was a child. As a child she felt victimized. She mentions that

these feeling of victimization has disappeared now that she is older. All the participants also indicated that they ignored people who called them names.

Despite being imposed on by the other regularly, the participant's general consensus was to ignore the rudeness of others and to not engage with them on their level choosing, instead to take the higher moral ground. All the participants indicated that there was a certain measure of restraint that they continuously exercised when dealing with others.

**d.      *Voluntarily ignorant***

The perception of the participants is that the other behaves in a manner that demonstrates their ignorance. The derogatory name calling of the other is perceived by the participants as a demonstration of a lack of knowledge.

*Participant 1: "Well basically it's because they are ignorant. They don't know neither do they want to know..."*

*Participant 2: "...you think that they just being ignorant..."*

The participants believe that the ignorance of others is a choice. None of the participants indicated that their Albinism aroused or drew the myths from others but that others were accountable for their own misguided beliefs.

**e.      *Higher tolerance for children***

Despite regularly encountering people who don't know about Albinism, the participants still had an expectation of the other. Their expectation was that adults should know more about Albinism. All the participants in the three focus groups expressed an increase tolerance of children who did not know about Albinism but little patience with adults.



*Participant 1: "...like when a child comes to me and calls me 'mlungi' and greets me in English I understand it's a child because they don't know but when an adult does it I just ignore them cos they should know"*

*Participant 2: "...but for children it's understandable... They hear what adults call us so they use those words, so I try as much as I can to teach them about us."*

*Participant 3: "For children it's different. You can understand, but now for adults its irritating cos by now you would think that they have some knowledge about us. So it's quite irritating when you have someone older than you especially and calls you 'eshowa'."*

All the participants believe that adults should know more about Albinism than a child. An adult should know not to be prejudiced. One participant explained that children imitate adults. Children are unaware and they don't know it's wrong or rude to call someone certain names because the children hear it for the first time from the adults. All the participants showed empathy and patience towards children. Participants took the time to teach children the proper way to speak and the proper terminology to use.

#### **4.5.4 Sub-theme 4: Treated differently by family**

It emerged in all three focus group discussions that the participants all felt that their families treated them differently because of their Albinism. Participants described an overprotectiveness of their families. Several reasons were offered for the over protectiveness of family members ranging from protective reactions of family members to stigma to safety concerns due to Albinism.

##### **a. Overprotectiveness due to social shaming**

Families of the participants are overprotective of them because of the offensive names that others call them. A participant described an incident that explains how her family is overprotective of her due to her Albinism:

*Participant 1: "In my family I have a cousin, 3 years old, and he is very protective over me. When I walk with him in the street when we going to the shop and some children call me those names he will actually want to fight cos he says nobody must call me that"*

Even at a young age family members understand that others are nasty towards the participant because of her Albinism and he wants to protect her from the derogatory names that others call her in the street. At the young age of three he wants to retaliate against the people who behave meanly to his family. This description of a little three year old cousin who gets upset if anyone calls her ugly names shows that he wants to protect her by challenging those who had called her names. This demonstrates that the relationship of the family members who are normally pigmented will also be affected by having an Albino relative. Simple activities such as walking to the shop can easily become an aggressive confrontation. None of the participants spoke of having this confrontational attitude with others.

#### ***b. Health concerns***

The sun poses a threat to the participants with Albinism due to a lack of melanin production. The participants said that their parents are aware of the threatening sun and are constantly vigilant:

*Participant 1: "They (family) are overprotective. They are always nagging and they say you must wear a hat...ya, ya, ya."*

Participants described the incessant nagging by their parents to wear hats and sunblock. The constant worry about the sun is prevalent in the daily lives of all the participant's families. The family is aware that the sun can cause blistering and severe skin damage to their child with Albinism. This anticipation of the pain motivates the family to give special attention to this aspect of Albinism. The nagging is motivated by care and concern for the wellbeing of the participant who could be harmed by the sun.

### **c.     *Reaction to stigma and mythical beliefs***

Many myths surround Albinism including that Albinos can cure AIDS and HIV. This motivates cultural healers like sangomas to take extreme action like kidnapping and killing Albinos in an attempt to capture their mystical healing powers. A participant said that her family were very aware of this threat to her safety and that it made them overprotective of her:

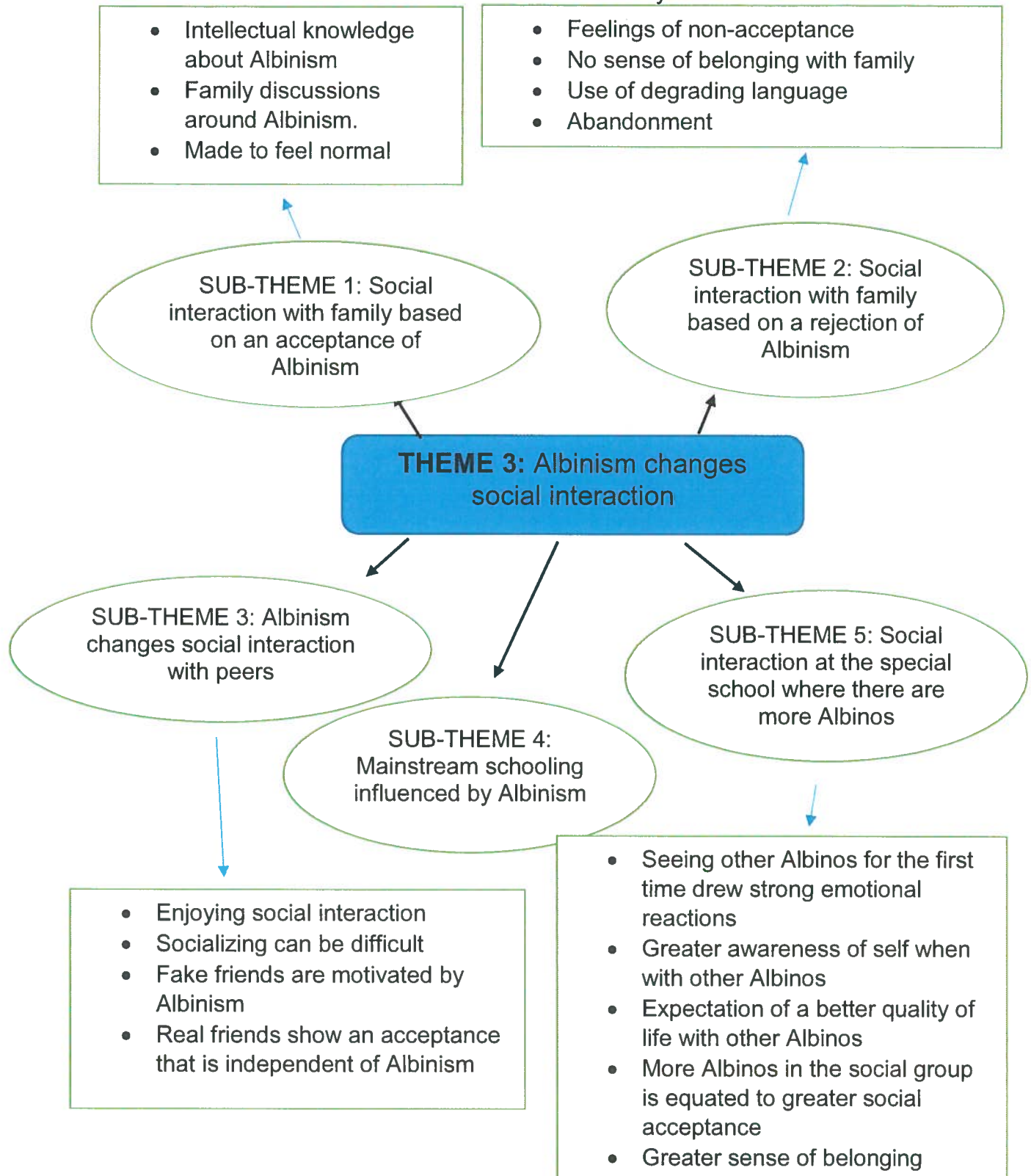
*Participant 1: "They (family) are overprotective because they still believe that there are people who kidnap Albinos because they going to make muti..."*

The belief that others have in the myths that surround Albinism present the participants with a social threat. Parents and family of the participants are aware of this danger. The awareness that others could harm the participant because of her lack of pigmentation is a concern for the family. The false belief that the society has about Albinism affects the family's behaviour towards the Albino participant. She is expected to make protective compensations for others who may put her at risk.

## **4.6 THEME 3: ALBINISM CHANGES SOCIAL INTERACTION**

Social constructs are the main determinant of reciprocal social interaction for the participants. Social constructs designing the psycho-social reality of the participants include social interaction with family, peers, mainstream schooling and at the special school. Figure 3 outlines the subthemes that emerged from the focus groups.

FIGURE 3: Outline of theme 3 with sub-themes and layers



The participants spoke openly and comfortably about their respective families. All the participants lived either with both biological parents or with only their biological mother as the primary caregiver. None of the participants lived with extended family as a replacement for their biological parent. Each participant had a biological parent present in their primary residence. Albinism had penetrated family dynamics and most participants described reasonable attachment to their family. Only two participants described rejection of particular family members based on Albinism.

Albinism has in no way impacted on the participant's ability to form secure attachment relationships with their primary care givers. Attachment relationships can be seen at times when a child is separating from a primary care giver. These situations caused the participants distress as can be seen in the following quotes:

*Participant 1: "I cried when I came to this school because I was going to stay in hostel. I was going leave my family."*

*Participant 2: "I think I was six or seven and I cried because I was going to leave my family"*

*Participant 3: "For me, when my parents told me that I was coming to this school I was excited but when I got here it wasn't exciting because I was missing my family..."*

The participants in the three focus group spoke explicitly of their attachment to their family. Their attachment shows a normal pattern of attachment that developed at a young age. This primary attachment is the basis of all social interaction. All the participants indicated, at some point in the discussion, that they had a reasonable attachment relationship to their primary caregiver.

#### **4.6.1 Sub-theme 1: Social interaction with family based on an acceptance of Albinism**

It emerged in the focus groups that their Albinism had impacted on family dynamics. Although all the participants showed significant attachment relationships with a primary caregiver the broader family was also deemed important and impacted on the participant's social interaction. The participants noted several criteria of how they gauged family acceptance.

Most of the participants described feelings of acceptance by their families. Family acceptance, as perceived by the participants was able to be divided into the following sub-themes:

- Intellectual knowledge about Albinism
- Discussions around Albinism
- Made to feel normal

##### ***a. Intellectual knowledge of Albinism***

Those who were the first child born with Albinism said that their families had to learn about Albinism but that that their families accepted them.

*Participant 1: "They (family) know everything about Albinos... My mother told them about Albinism."*

The most prevalent answer when asked about family was that their family had intellectual knowledge about Albinism. This was a fundamental issue to all the participants who participated in the three focus groups. The extent to which the family had intellectual knowledge of Albinism was meaningful to the participants because it was perceived as an acceptance of Albinism. All the participants who were the first Albino in their family spoke about the intellectual knowledge of their respective families. They said that their family either had to learn about Albinism or educate others about Albinism. Parents had taken it upon themselves to educate others about Albinism on the child's

behalf. The mother is the primary source of information about Albinism for the extended family.

**b.      *Family discussions around Albinism***

The participants, however, explained that intellectual knowledge of Albinism was not the only measure of acceptance. Instead a combination of intellectual knowledge of Albinism together with a mundane or light-hearted discussions about Albinism as a measure of acceptance. Participants said that their family would speak about the lack of pigmentation caused by Albinism in a fun way. This method of communication is uplifting for the participants and they all enjoyed hearing jokes about Albinism.

*Participant 1: "They enjoy telling me that I change colours. The children, sometimes say I become red, sometimes I'm white." \*group laughs\**

Making jokes with family members about her skin colour was acceptable to all the participants. This type of communication reflects a social bond within the family. The participants also related family discussions about Albinism relating to mundane household chores. This shows a family dynamic around Albinism which includes the girls and shows that they are integrated into a family situation.

*Participant 2: "At home there's three of us, my oldest brother is non-Albino and then my brother is an Albino... Like you know Albino's have a visual problem and maybe sometimes you don't want to clean you'll say that you can't see the dirt. She'll tell you 'no, try to see it, use a magnifying glass if you have to so the place must be clean.' So family treats us all the same, everybody is the same."*

The dynamic relationships that the girls described in the focus group discussions mostly surrounded the family's daily life and how Albinism has impacted on mundane issues. Each child, irrespective of pigmentation is expected to do household chores. One teenager related using her poor

eyesight due to Albinism to try and avoid doing household chores. Her mother engages her in a conversation about the Albinism and told her to use her initiative and to make adaptations to compensate for her poor eyesight rather than letting her avoid doing household chores. This is an indication that her mother is trying to instil discipline in her despite her Albinism so that she must learn to care for the house like everyone else. None of the girls said that they discussed myths when they were with family members showing that the family did not subscribe to myths.

**c.      *Made to feel normal***

All the participants who were not the first Albino in their respective family used the word “normal” when talking about family.

*Participant 1: “In my family they treat me normal, they treat me like they treat all the other children, they don’t treat me differently just because I’m an Albino.”*

*Participant 2: “And in my family they treat me normal, I even forget that I’m an Albino sometimes.”*

*Participant 3: “...they treat me normal because I’m not the first one, I think my grand-grandmother (had Albinism)”*

A sense of normality with family is perceived by the participants as a show of acceptance. Participants reported that their integration within the family did not accentuate their medical condition but overlooked it. One participant attributed the normality of her family’s attitude to the fact that she had a previous family member with Albinism. Being born with an Albino relative seem to have an absence of a learning curve for family members. Parents did not need to learn about Albinism nor did they need to teach anyone else about Albinism.



#### **4.6.2 Sub-theme 2: Social interaction with family based on a rejection of Albinism**

A minority of the participants described feelings of rejection from significant family members although none mentioned the primary caregiver. A couple of participants said that they had significant family members who did not accept the fact that they had Albinism. This non-acceptance of the medical condition sometimes translated into overt rejection. Participants perceived rejection as:

- Feelings of non-acceptance
- No sense of belonging with family
- Use of degrading language
- Abandonment.

All the participants who described feelings of rejection from family members were the first born Albino child in the family. Not all participants who were the first born child with Albinism felt rejected by their family.

##### **a. *Feelings of non-acceptance***

Not feeling accepted by significant family members due to Albinism constituted a perception of rejection. As related in a focus group:

*Participant 1: "...our family, especially the old ones like my granny, God rest her soul, I think she never accepted who I was. She tried, because of her daughter being my mum, but deep down she never accepted who I was."*

The lack of acceptance as reported by the participant was due to the participant's lack of pigmentation. The rejection that the participant felt was a rejection of herself as a human person and not merely a non-acceptance of her Albinism. The participant relates that family ties were important but that it was particularly difficult for senior members of the family to accept a child born with Albinism. The participant relates that her mother played a pivotal role in her integration within the family but her elderly grandmother was unable to adapt her thinking to show affection towards her Albino grandchild

although there was always a level of tolerance that the girl received from her grandmother for the sake of the daughter.

**b.     *No sense of belonging with family***

Rejection from family was also perceived by the participants as them not fitting in with family members. A participant related that she felt no sense of belonging when she was with family and was merely more aware of her difference from family members.

*Participant 1: "Sometimes when all the family members are gathered and you sitting together, you just sit and look at yourself and ...you wonder 'why am I like this, why did God make me an Albino'."*

Despite sitting together with family members she was aware of her difference due to her lack of pigmentation. The participant spend time thinking about her difference when she was with family members. The thoughts of their skin colour penetrate their spiritual relationship with God. She believe in God as a creator of all things including Albinos.

**c.     *Use of degrading language***

A participant described incidences that made her feel rejected by a family member when degrading language was used to describe her Albinism.

*Participant 1: "When we used to argue she (grandmother) always use to say, when I pressed the wrong buttons and she used to say 'eshowa' and I'm like 'how can my grandmother say something like that!'"*

Conflict management is an integral part of family dynamics and the participant admitted to provoking her grandmother but she felt that the response she received from her grandmother was unacceptable and derogatory. The participant interpreted the use of foul language as a rejection based on her

lack of pigmentation because the specific swearing word used refers to the participant's appearances due to the Albinism.

#### **d. Abandonment**

Abandonment of the Albino participant as a child by significant family members is perceived as a rejection. One participant related a painful incident showing that her father rejected her Albinism and abandoned her and her mother.

*Participant 1: "In my father's part of the family they never accepted the fact that I'm an Albino. I think even now that's a problem because they believe that my mother was cursed. That is the reason that I am being raised by a single parent..."*

One participant revealed that her father abandoned her and her mother because of her Albinism. She explained that a belief in myths that surround Albinism that was imposed onto her at birth. The myth was extended to her mother. Her father used these myths to justify his abandonment.

#### **4.6.3 Sub-theme 3: Albinism changes social interaction with peers**

During teen years the friendships with others are important. The participants discussed having fake friends and genuine friends. The crux of the group discussions surrounded Albinism and how the medical condition influenced emergent friendships. The participants in different focus groups expressed that their Albinism impacted on social friendships with others. The social relationships that were discussed amongst the participants covered friendships with non-Albinos and friendships between Albinos.

All the participants mentioned preferences in the types of people with whom they socialize. An emerging theme is that the participants do socialize with others, although different participants indicate different preferences of socializing. There was no single criteria for socializing that can be specifically related to Albinism. Some participants enjoy socializing, some avoided

socializing and some indicated a preference for socializing with groups of people that were well known to them, either by way of family, church or at the special school. None of the participants indicated that they avoided all socializing at all times.

**a. *Enjoying social interaction***

Some participants expressed enjoying socializing. Incidents were described where the participants enjoyed participating in social events to help their church. Some participants indicated a clear rule that they exercised in regards to socializing. Some participants expressed an overall enjoyment of socializing with others whom they did not know:

*Participant 1: "I like meeting new people."*

The participant's perception of socializing is that she enjoyed meeting new people. At no point did she group all strangers into the "them" box of people who yell insults or believe in the myths that surrounded Albinism. She still saw people as new and exciting.

The participants reported that new people react in different ways to their lack of pigmentation. One girl describe other people as "curious" about Albinism. It was reported that in new situations, people were interested in her because of her appearances.

*Participant 2: "... (they) try and make new friends so that they would understand how we live and how we cope with Albinism."*

This participant enjoyed socializing because she didn't mind people asking about her Albinism. She spoke freely about Albinism with strangers, whom she perceived as interested. She believed that people were trying to make friends with her by engaging in conversations about Albinism.

All the participants reported that they enjoyed church, describing it as “nice” or “fun”. Sometimes they were deliberately thrust into the limelight in some social situations due to their lack of pigmentation. In these instances the girls would consent to being in the limelight because they understood that it as socially appropriate and a mark of veneration.

*Participant 3: “...In church, when the big Minister is presenting they always ask me to be in front even though people of my age aren’t allowed to do certain things, I’m an exception. I don’t know what it’s called but when the apostle comes, that’s the big priest, children carry flowers for him and sing but I still do that and I’m meant to being front even though others my age are not allowed to (carry flowers)...(It’s allowed) because I’m an Albino and they want to make their whole image shine.”*

The perception of the participant is that her participation in the event uplifts the entire congregation. She feels appreciated by her church and her religious group. She understands that the importance of the event and accepts the role offered to her as a benefit to her religious community. She never spoke of anyone in the congregation objecting to the accommodation of a mature Albino in the procession. Thus it can be understood that the rest of the congregation accepted bending the rules for an Albino because she was an exception.

*Participant 4: “For me it depends, if it’s something that has to do with the family, I go. But if it’s something outside, like my mother’s friend, I don’t go”*

The participant was not averse to socializing but she was careful with whom she socialized. She had a preference to socialize with family. She indicate a general avoidance of socializing with people outside her family. This can be understood as it is easier for the participant to socialize with people that she knows and with whom she is familiar. She prefers to not meet new people.

**b. Socializing can be difficult**

Later in the focus groups some participants mentioned that at times they prefer to avoid social situations. Some social situations can be difficult for the participants:

*Participant 1: "I don't like meeting new people, like when my family goes for weddings I just stay at home."*

Some participants expressed an avoidance of people that they did not know and avoided meeting new people. In another discussion group a participant explained why she preferred avoiding meeting new people:

*Participant 2: "Well, when you meet new people sometimes, it makes your feelings tough. I personally sort of isolate myself from the crowd because somehow I feel that they not going to accept me for who I am so I like to isolate myself from the crowd."*

Participants explained that it can be hard to socialize with strangers because they are concerned that they will be rejected. Isolation from the crowd was a way to protect themselves from rejection. The rejection was painful for the participants and hurt their feelings. This alludes to a fear of rejection of new groups due to Albinism.

The fear of rejection in meeting new people is not the only way that the participants believe that their Albinism affects socialising. The participants believe that their medical condition impacts on their social friendships:

*Participant 3: "When you get friends you'll have fake friends and real friends"*

All teenagers grapple with the difficulty of who to trust. The participants explain that their lack of pigmentation helps them to distinguish between fake friends and real friends who have normal pigmentation.

**c. Fake friends are motivated by Albinism**

During the focus group discussions several criteria of how the participant's perceived fake friends emerged:

*Participant 1: "Some will be your friend cos you an Albino and they want to look cool."*

*Participant 2: "Yes. Some will actually say that 'I'm cool, I have a white friend' so they say."*

*Participant 3: "Some people like being seen around with me and that's the only problem I have."*

Participants in various group discussions said that fake friends felt that it was fashionable to be seen in public with an Albino and that it boosted their image. Fake friends, according to the participants, relate having an Albino friend to an acquisition of status. Fake friends made the participants feel more self-conscious. The participants were all aware of ulterior motives that the fake friends had to be seen in public with an Albino. This is a manipulation of the participant to use their Albinism to gain social status. Participants in differing groups said that people who are motivated to be their friend because of their Albinism are a concern indicating that the participants view them with suspicion and deem them untrustworthy.

**d. Real friends show an acceptance that is independent of Albinism**

Several factors emerged from the focus group discussion that the participants valued in what they termed 'real friends'. These factors include having a few jokes, sharing common interests and being able to relate to each other. Overall, participants agreed that when they are with real friends that they are less self-conscious and they feel accepted as the person that they are.

The participants said that real friends did not emphasise their appearances and helped them forget that they have Albinism. Other important factors in real friends, as perceived by the participants, can be seen in the following quote:

*Participant 1: "My friends are my friends like real friends, when I'm with them I forget that I'm an Albino. I feel like I'm them, to the extent that if I would see an Albino walk by when I'm with them, I'll be like 'How! Look. There's an Albino!' I'll be surprised, like how they get surprised when they see Albinos. Ya, that's how my friends are."*

The participant described her social integration with her non Albino friends and the acceptance that she feels when she is around them. She identifies so strongly with her non Albino friends that she adopts their way of thinking. Her self-concept changes and she becomes 'one of them' indicating a sense of belonging and trust. Social competency was an important aspect of friendship for the participants. Having Albinism was not a criteria for a friendship instead sharing interest is important to the participants as illustrated below:

*Participant 2: "Not all (my friends have Albinism), but I think they can relate because somewhere down the line we share the same interests."*

Sharing interests and connecting with another person is important in friendships for the participants. Here the participant indicates that not all her friends have Albinism. Those of her friends who do have Albinism are her friends because of social reason such as common interests.

#### **4.6.4 Sub-theme 4: Mainstream schooling is influenced by Albinism**

Only a few of the participants in the research study went to mainstream school before attending a special school. In the first group the only girl that went to a mainstream school said that it was normal for her. Her experiences in the mainstream school were not traumatic and she said that she had made friends at school.



*Participant 1: "They treated me like I was special. Since I was a kid I never noticed (the Albinism) so it was normal for me. Everyone treated me normal."*

In two of the three focus groups the participants described being bullied at the mainstream school that they attended before entering special education.

*Participant 2: "Bullying. They were like 'YOU!' and I was like 'Guys I'm like you' and they didn't understand..."*

*Participant 3: "Children used to laugh at me."*

Despite their efforts to try and explain to other learners that they were just like them, they were ostracised. The bullying at a mainstream school consisted of verbal abuse, mocking and even physical attacks.

*Participant 4: "...and there was one boy that used to hit me when we were going home ..."*

*Participant 5: "They used to call me names and they sometimes call you a white, they think you are white. And they call you 'mlungi' or they will call you 'eshowa'."*

The participants describe regular physical attacks, mocking and bullying from other learners at the mainstream school. The participants described that they were helpless. Reporting the transgression of others to their parents were futile:

*Participant 6: "... I was so quiet and if I report this at home my mother use to say it's usual, they didn't understand (girl cries)..."*

*Participant 7: "I used to cry."*

None of the participants who spoke of the bullying that they experienced said that parents or teachers would intervene to protect them nor that any effort

was made by an authority figure to educate the learners on Albinism. Parents seem to think that it was acceptable for a pigmented child to have no understanding of Albinism. The parent did not make an effort to protect her daughter from being hit by a boy at school. The parent did not think that it was inappropriate for a boy to hit a girl. The girl's lack of pigmentation superseded the gender of the both children involved. This left the Albino girl vulnerable and unsupported.

#### **4.6.5 Sub-theme 5: Social interaction at the special school where there are more Albinos**

The participants reported that the contradiction of having Albinism is that they themselves are not accustomed to seeing other Albinos. Meeting other Albinos for the first time was a momentous occasion for all the participants. None of the participants mentioned that they had known anyone with Albinism that was not related to them before entering the special school.

*Participant 1: "For me it was weird because when I grew up I knew that it was only my older brother and myself who are Albinos... You'll be scared like you have never seen another Albino besides yourself and your brother, it used to be like the two of you, aliens. So it was kind of surprising."*

The participants in two focus groups reported that they have never seen any Albinos outside their family before. It made them uncomfortable to see other Albinos. Being solitary was a norm for the participants with Albinism and being in a group with other Albinos was initially difficult and needed some adaptation. Being in a group of people with Albinism was surprising for the participants and it evoked an array of emotions.

All the participants described emotional turbulence at seeing other Albinos. Some expressed hope, some surprise, some expressed fear and apprehension. Seeing other Albinos had meaning to all the participants. Some had an expectation of belonging and acceptance. Some said that they become more aware of themselves and how they look. Some immediately identified with other Albinos. Some were unsure and cautious.

**a. *Seeing other Albinos for the first time drew strong emotional reactions***

Witnessing others with Albinism for the first time evoked an array of emotions for all the participants. None of the participants mentioned that they could not remember the first time that they saw a group of Albinos together. As a participant described her initial reaction to seeing groups of other Albinos when she first entered the school:

*Participant 1: "When I came into this school, all these Albinos, I was kind of scared and happy, but scared like 'WOW!' so many people like me so you would be happy to see that but WOW!"*

The participants described their emotional reaction as ranging from shock and fear to joy. The initial shock was attributed to the fact that there were so many people with Albinism at the special school. Seeing a large number of people with Albinism was surprising because she had never seen any other female with Albinism before.

*Participant 2: "Eish, I was a bit scared when I came here and meeting other people, and all the Albinos here. I didn't know that it was a school for Albinos. It was difficult but I managed."*

A participant expressed anxiety when moving to a new school. She attributed her apprehension at changing school because meeting new people, irrespective of whether they had Albinism or not, was difficult for her. Coming to a school where there were more Albinos was apprehensive not because of the Albinism but because the fact that they were strangers to her. Another participant agreed with her saying that she was also afraid of the new environment.

A participant related that being uninformed that there would be other Albinos at the school contributed to her surprise. Despite the initial fear the participant

said that she adapted to the new environment. Participants identified with other Albinos saying that they were like her.

**b. Greater awareness of self when with other Albinos**

Many participants had said that they were more aware of their Albinism. When they were in a group with other Albinos at the special school. Participants expressed a greater self-consciousness when seeing other Albinos. Seeing other people with Albinism made them more aware of their own appearances.

*Participant 1: "Sometimes it's a little awkward, like when you meet different people or are in a different community and are not use to seeing them (Albinos around) and when I'm in school I see a lot of them (Albinos) it's kind of a little awkward. When I'm home I usually don't notice or look at it as different but when I'm in school I can't help notice."*

The participants said that when she was at home and there are no other Albinos around she didn't notice her differences and when she's around other Albinos she is more aware of her appearances. This made her feel self-conscious and awkward.

**c. Expectation of a better quality of life with other Albinos**

Seeing other people with Albinism for the first time had meaning for the participants. One participant expressed the hope that it inspired in her:

*Participant 1: "I was happy, cos I saw some people same like me and I thought life will be better and different."*

Merely seeing other people with Albinism revived hope inside the teenager. She aspired to a better life compared to the life she had at a mainstream school. She had hoped that her life would be different from living alone in her community as a solitary Albino. The hope that she expressed related to having friends with Albinism and the absence of threat and harm.

***d. More Albinos in the social group is equated to greater social acceptance***

All the participants agree that there is more social integration of Albinos at the special school because there is a larger number of learners with Albinism. It is easier to meet others with Albinism with whom they share common interest and it is easier to meet pigmented people who have accepted Albinos as friends. A participant reported:

*Participant 1: "With friends it's not hard cos we can relate, like we share the same skin colour and most of us have (non-pigmented) friends at school so it's not hard cos they understand."*

The participants perceived that it is easier to find social acceptance within a population where there was a larger Albino population. Finding people who share your interests was easier. Even non pigmented peers were more understanding and accepting of the participants. The greater the number of Albinos in the broader social group, the better the social integration of the participants even amongst non-pigmented learners at the school. None of the participants reported any bullying or intrusive behaviour of others at the special school where there is a large number of Albinos. This demonstrates social integration of the Albino participants with normally pigmented peers and staff.

In the group discussions it emerged that people with Albinism related better to each other. Having Albinism, however, is not a guarantee of social friendship amongst Albinos. Every participant who had Albinism was not friends with every other Albino at the special school. None of the girls said that they experienced harsh language, name calling, myths or abuse from others at the school due to their lack of pigmentation. During all the group discussions the girls reported that they had made friends at school even though some of their friends were normally pigmented.

**e. Greater sense of belonging**

The participants spoke about how being at a school with so many other Albinos changed the way in which they saw their Albinism and themselves. Several reasons arose that accounted for the change in self-perception when they were with other people with Albinism:

*Participant 1: "For me, living with Albinism used to be very hard ...I felt like I didn't belong... but now, when I came to this school, I saw that there's nothing wrong with being an Albino and I accepted who I am"*

*Participant 2: "You feel comfortable (around other Albinos) and you feel like you have a sense of belonging"*

A participant spoke of the difficulty she had living as the only Albino in her family and in her community. She felt isolated from the community where she lived due to their negative view of her Albinism. Being at a school where there is a greater population of Albinos has changed her perception of Albinism and improved her self-concept as an Albino. Previously she believed that being an Albino meant that there was something wrong with her but now she has accepted herself as being more than just an Albino, she has found a self-acceptance of herself as a person. Another participant said that she was more at ease in an environment where there was a larger population of Albinos. She described a greater sense of belonging because she was in an environment that was more accepting of her Albinism. As one participant related about being at a school with other Albinos:

*Participant 3: "... now I'm able to communicate with others and have some jokes"*

Participants related that when they are at a school where there are more Albinos they automatically feel better. Feelings relayed about being around other Albinos included better communication and jovial light heartedness.

#### **4.5 CONCLUSION**

Three main themes emerged from the three focus groups that were conducted at the special school. The first main theme that emerges was the perception of difference that society had of the participants. This perception of difference lead to the second theme that emerged which is that the participants felt that people treated them differently because of their Albinism. The third theme was that social interaction with others changed because of Albinism. The application of the psycho-social group framework in the next chapter will outline the impact that the participants experience have had on the development of a group identity.

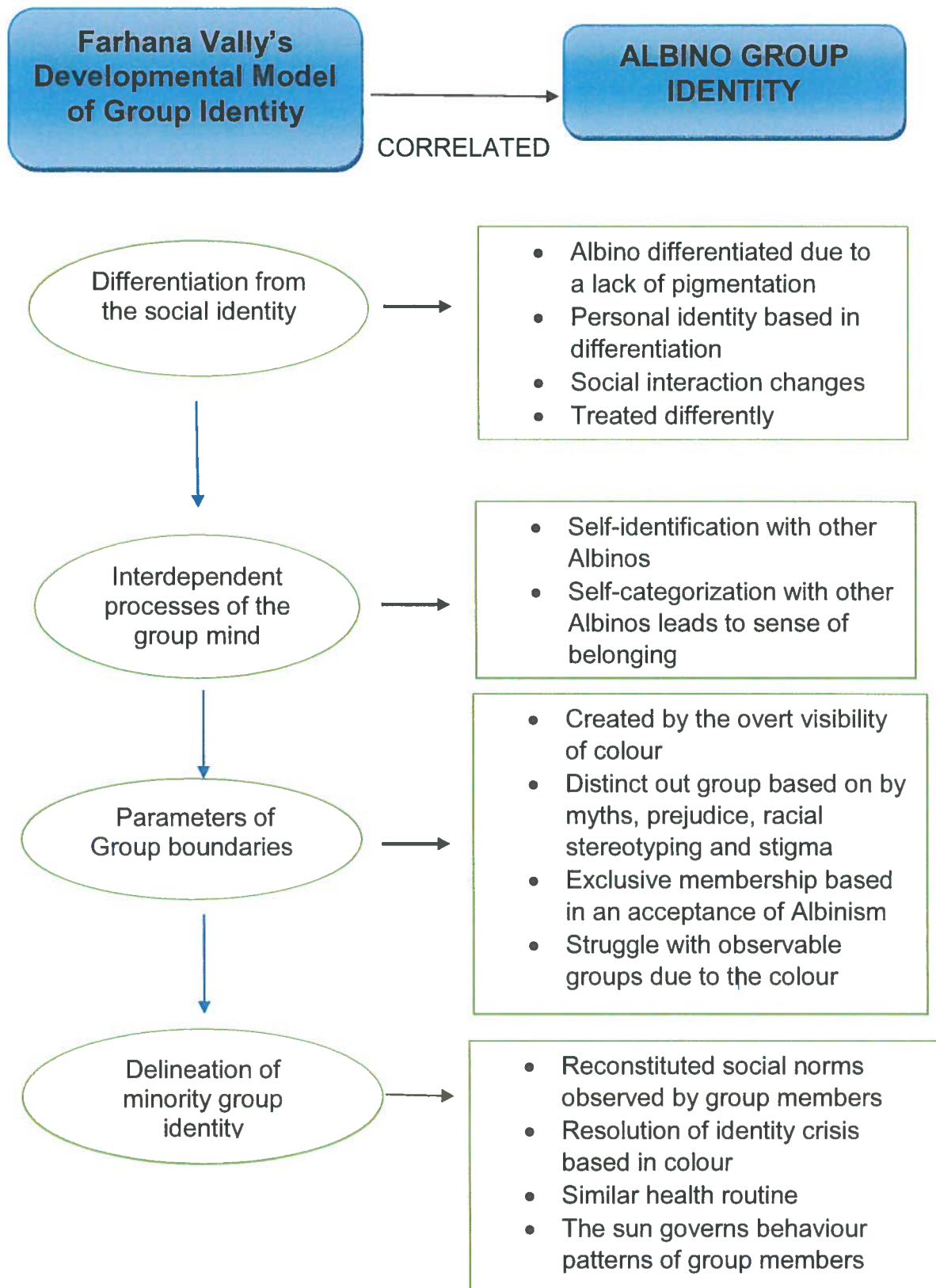
## **CHAPTER 5: DISCUSSION**

### **5.1 INTRODUCTION**

Chapter Five is an integration of the findings with the theory outlined in Chapter Three (Literature Review). The researcher summarizes the theoretical framework in Figure 4 as Farhana Vally's Developmental Model of Group Identity Development. Albino Identity is correlated to theory in order to appraise the group identity, outlining distinguishing factors of Albino Group Identity.



FIGURE 4: Farhana Vally's Developmental Model of Group Identity correlated to Albino Group Identity integrate findings and theory



## **5.2 THE SOCIAL IDENTITY SHAPES THE PERSONAL IDENTITY BECAUSE OF A LACK OF PIGMENTATION**

Meaningful factors from the social identity that were identical for all participants could be identified according to Farhana Vally's Developmental Model of group identity. Three key facets emerged, namely:

- The social identity differentiates the participants because of a lack of pigmentation
- Albinism belies the social norm of pigmentation is entrenched in the social identity, undermining the collective unconscious and
- The social identity creates myths and traditional beliefs in the group mind as justification for the colour of Albinism

These three facets have designed the personal identity of each participant in identical fashion. The above mentioned stipulations have adapted the personal identity of the participants in the following manner:

- Each participant had an opinion of the three facets of social identity
- Personal opinions differed as per participant
- All opinions had identity value to the participants
- The shared ideas stemmed from shared lived experiences which constituted a group identity

The personal identity of the participants emerged in the focus groups through healthy discussions and contrasting personal opinions about the same subject. The personal identity is based on the personal experiences of each participant and how they have each interpreted events to have personal meaning. Personal identities may be different despite similar experiences because each participant will interpret their experience differently.

### **5.2.1 Social Identity differentiates participants due to a lack of pigmentation**

Differentiation from the social identity is the first step in Farhana Vally's Developmental Model of group identity. The social identity has given the participants the label of different which is meaningful to the participants. This theme of being different is created by a lack of pigmentation. The difference is

the colour created by Albinism. Skin colour is an important part of the social identity that exists prior to the person who is born without pigmentation (Dalal, 2000).

The participants accepted that they are different because they lack pigmentation. A participant articulated that she sees herself as different because others saw her as different. This is evidence that the participant's personal identity has been altered by society's perception.

### **5.2.2 Albinism contradicts social norms of pigmentation and colour**

The participants explained that they do not conform to social norms because they are not seen as being "black like black people". The colour of the participants that is a contravention of a social norm. Society believes that light skinned people are Europeans and that dark skinned people are Africans. This violation of a social standards has lead society to brand the participants as different.

The social identity is reflected in individuals who adhere to social norms with uniformity. Mann (1969) explained that negation of social norms is intolerable because it undermines the continuity of society. Public behaviour towards the participants is evidence of intolerance which translates into a rejection of the Albino herself.

Differing opinions about the 'whiteness' emerged from participants ranging from positive, negative or insignificant. The personal perception of the participant determined the participant's attitude and behaviour in managing the social identity. Some participants believed that being without pigmentation made them special. This view point was challenged by other participants who believed that being white does not make them special. Participants were confident in expressing their viewpoint without fear of rejection from the group. It is also a demonstration of the absence of regressive phenomenon amongst the participants. Thus, Albino Group Identity has aspects that the participants share but these shared aspects of their identity does not overpower the personal identity of the participants.

The participants felt that their difference was the source of capturing the attention of others. In accepting that they are the source of drawing the attention of others the participants identified their colour is an attribute that warrants the attention. Participants all adapted to drawing attention and were obligated to deal with the attention directed at them. Thus the participants all reconstitute their behaviour to compensate for the behaviour of others (Goffman, 1975). This shows acceptance that their difference is the source of the obtrusiveness of others. Each participant compensated to deal with the morbid curiosity and stigmatization of others (Goffman, 1975). The attention from others often lead to a lack of anonymity in public for the participants. Drawing the attention of others and a lack of anonymity is a group norm for the participants courtesy of the social identity. The personal identity of participants varied. Some participants relished the attention and some were indifferent. Some participants said that they would not like the attention and they wished that people would stop giving it to them, preferring to avoid it.

### **5.2.3 Social identity creates myths around Albinism**

Others can see that they (the participants) are '...not white and not black...' People add meaning to the colour of Albinism to resolve this conundrum. Cognitive dissonance of other people lead to the social identity informing the justification for the participants colour through myths. Myths are imposed onto the participants, shaping their Albino Identity, corroborating Blakenberg's (2000) study.

People have turned to traditional beliefs to resolve dissonance and explain Albinism. A participant noted that people don't want to know about Albinism. It is easier for people to believe in myths and instinctual ideas. This demonstrates the inability of the group mind to relinquish a societal belief. The belief that African must have pigmentation is a fundamental belief that people are unable to adapt to despite witnessing a person without pigmentation. Thus people react so that the existence of the participant's colour fits in with their belief system.

Myths are traditional stories that comprise archetypes (Swoden, 2006). The two most commonly encountered archetypes described by the participants were the archetypal magician and the archetypal healer. The stories encountered by the participants have either exalted the participants to deities or degraded them as magical curses. Both instances reject the participants as other than normal because of their colour (Goffman, 1975).

People associated the archetypal healer with Albinism to explain why the participant's appearances. The archetypal magician justified the existence of the participants, exempting them from a human birth and death. The exaltation of the participants to superhuman status was what Goffman (1975) wrote as 'other than normal'.

People find the white colour of the participants so exceptional that they associated the lack of pigmentation with supernatural powers. The white colour was associated with divine power, ancestral wrath, blessings, magical appearances and disappearances. People thought that the participants appeared white because they possessed divine powers and were able to bless or curse people. Others believed that they are able to transfer the white colour to others through touch or that they incurred the wrath of God.

Myths are a type of projection from the collective unconscious (Snowden, 2006). People wanted the lack of pigmentation to mean something and then projected it onto the participants. People used the existence of the participants to justify their false beliefs. As the participants explained people treated them differently because of a belief that the person without pigmentation has magical powers. Myths that surround Albinism has identity value for the participants. Each participant rejects the myths and have employed a deliberate strive for normality which is a group norm in Albino Group Identity.

Although all the participants had encountered the myths that others had about Albinism, each participant showed a different reaction towards people who believed in myths reflecting their personal identity. By accepting that the belief

in myths is part of the others identity and worldview a participant said that she enjoys spending the money she gets because other people want to believe in myths. This shows an understanding that she, as an individual, will not be able to change society's mind and that she can only control her reaction to the behaviour of others. This is a demonstration of mature individuation in identity formation and it shows a separation of minds from the collective unconscious. This participant shows that she does not share in the value system that the group mind informs others. Yet, she understands the value system of the other. Through the process of individuation she has now differentiated herself and changed her perception of other people. In doing this she has changed her behaviour and attitude towards others. This can be seen as a coping strategy which is a reflection of her individuated personal identity that reflects the broader social identity and is altered by it.

Most of the participants expressed irritation or annoyance at the belief that others had in myths but prejudice epithets were ignored. Yet, these opinions are part of the daily life of the participants and shows that all the participants have been changed in the same way through the social interaction with other people. Participants reported that the prejudice of others was hurtful when they were younger but that they are able to ignore it as they matured. This shows a reconstitution of behaviour of the participants as an adaptation to the social identity (Goffman, 1975).

### **5.3 COMMON SOCIAL EXPERIENCES THAT ARE MEANINGFUL TO THE PARTICIPANTS CREATES A SHARED PERSONAL IDENTITY**

Step one in Farhana Vally's Developmental Model identifies an alteration in social experiences as a mechanism of differentiating a minority group identity from the social identity. In the focus groups it emerged that Albinism changed social interaction for all the participants. Factors of the social identity governed the social interaction of all the participants. Meaningful social interaction has led to an exchange between the social identity, personal identity and group identity of the participants (De La Rey, 1991).

The participants felt that they were treated differently because they were Albinos. Social norms govern social interaction (Slater, 2004). The psycho-social group framework offers several reasons to explain why the participants are treated differently by society. Thus people treat the participants differently because their colour contravenes a social norm due to Albinism. People treat the participants differently by giving them attention, racially stereotyping them, prejudiced epithets or imposing a belief in myths onto the participants. Goffman (1975) explains that the social identity will inform the stigmatized person what she should think of herself. Thus, the social identity changes the way people treat the Albino participants. The participants explained that the way family treat them is more meaningful than the behaviour of strangers.

#### **5.3.1 Treated differently because of a lack of pigmentation**

The participants reported that people treated them differently because of their lack of pigmentation. The social identity governs the behaviour of people exhibiting typical patterns of behaviour in reaction to the non-conformity of Albinism. Typical behaviour patterns encountered by the participants was based in prejudice, racial stereotyping and a belief in myths. Strangers often question their colour expecting the participants to justify their appearances.

#### **5.3.2 Treated differently because of stereotyping**

Others would try to racially stereotype the participants and speak to them in English. People adopt behaviour patterns of the social identity when they are in an anxious state (Giddens, 1991). Therefore it can be reasoned that people find the witnessing of an Albino anxiety provoking because they have turned to traditional beliefs. The social interaction between the participants and other people informs the participants that society thinks that they should be English because of their colour.

### **5.3.3 Treated differently because of myths**

Beliefs in myths surrounding Albinism directly translated into the participants being treated differently. Strangers would try to touch them to gain blessings or people would avoid them for fear of contracting Albinism. This behaviour would be inappropriate behaviour in social interaction. Goffman (1975) explains that because the stigmatised person contravenes social norms that they are relinquished of being extend the same courtesies as 'normals'. The interaction order of appropriate social interaction is compromised because the participants do not conform to the social rule of having pigmentation.

### **5.3.4 Treated differently because of prejudice and stigma**

Prejudiced epithets reflect what Le Bon (1896) called the primitive and irrationality of crowds. Others yelling insults at strangers in public, as was experienced by the participants, shows a lack of impulse control. This primitive mind has a heightened capacity for aggression and even violence (Le Bon, 1896). The participants reported incidence of violence and aggression in the focus groups. Others tend to react to the participants with aggression due to the non-conformity of the Albinism.

Prejudices behaviour is what Goffman (1975) called stigmatization. The branding of someone as other than normal by society. The participants felt that people labelled them as different which constitute an 'other-than normal' label from society. Goffman (1975) said that the label is given to the stigmatised person because society considers her to be inferior and she is therefore excluded from social acceptance. The prejudiced behaviour of strangers towards the participants reflect the social identity that considers them inferior because of their skin colour. All the participants spoke of being called derogatory names like "eshowa" and "mlungi". Prejudiced labels represent the hostile expulsion of the participants from acceptance by African society. Society inform the participants what it thinks of them in an overtly aggressive manner. This study corroborates findings by Magnus (1992) that the participants with Albinism are ostracized by the fellow citizens.



### **5.3.5 Family treat the participants differently because of Albinism**

The perception that the participants have of their respective families in relation to Albinism will be explored. The study found that participants perceived their families and the special school in the same way. The family's reaction to Albinism was an important factor in shaping the Albino Identity of the participant.

#### ***a. Personal identity of the participants shaped by overprotective family***

All the participants reported that they felt that their families were overprotective of them. The participants explained that they understood why their families were overprotective and gave several reasons. Justifications varied from health and safety concerns to protective behaviours. Families shared health concerns about the harmful sun and safety anxieties because people believe in myths. Families cared about the prejudice and stigma directed at their Albino children. Families are reportedly 'knowing' of their daughter's stigmatic condition (Goffman, 1975).

The participants indicated that the 'knowing' of the family creates concerns for their families who want to protect them. Knowledge of the stigma attached to Albinism creates fear which reveals the danger sooner (Freud, 1939). Goffman (1975) called this the dilemma that families are faced with when their stigmatized child ventures into the world. The overprotectiveness described by the participants were in contexts where the participants would leaving the home.

The overprotectiveness of the participant's families is an illustration of interdependent processes whereby the social identity shapes personal identity and group identity (De La Rey, 1991). Families suffered the same social deprivations endured by the participants. Deprivations included myths being imposed onto the parent, the parent being stigmatized and rejected because of Albinism. Parents and families of the participants live with a courtesy

stigma because their child has Albinism, corroborating Goffman's (1975) theory of Spoilt Identity.

Overprotectiveness of families is motivated by fear that has been created by the social identity. The parenting role is now defined by fear and worry. Yet, worry is a way to relieve cognitive dissonance (Slater, 2004). The fact that the lack of pigmentation creates cognitive dissonance in the group mind and the participant's families is evidence that the families also have a share in the social identity. The families share in Albino Group Identity, though, changes the way that the social identity is acted out (Wetherell, 1996). Both society and the family have to relieve cognitive dissonance caused by Albinism. Society resolves it through myths, traditions or stigma and the family resolves dissonance through worry. In both instances the dissonance changes the way that the participants are treated. The way that others and family treat the participants represents the social interaction that arises from the social identity. Social interaction is the primary organiser of the psyche and group identity (Dalal, 2002). The social identity has changed the way that family treat the participants changing the shared personal identity of the participants.

***b. Family relationships underpin the personal identity of the participants***

Most participants, however, described a sense of belonging with family with the exception of two participants. Most of the participants did not see the overprotectiveness of their families as not normal which demonstrates what Goffman (1975) called an engulfment of domestic acceptance. The participants understood the motives for their family's overprotectiveness which allowed them to accept the behaviour as normal. The participants identified with their families. This study corroborates Goffman's theory that the stigmatized person who is engulfed with domestic acceptance showed a higher alignment with 'normals' amongst teenaged girls with Albinism (Goffman, 1975). Most of the participants demonstrated their alignment with their normally pigmented family by saying that they still participated in family outings or sharing jokes about Albinism with family members. Family

acceptance of Albinism was perceived by the participants as the discussion of Albinism without myths and traditional beliefs and being treated normally at home despite the overprotectiveness of their families when participants ventured outside.

The formation of early attachment relationships reflects the sense of self that is reflected in adolescence (J. Kroger, 2007). The participant's related stories that show that the family's safety concerns did not affect their attachment to their families. This was especially evident when the Albino participants had to leave their families to board at the special school. The stigmatic status of the participants did not affect the attachment relationship with their families.

***c. Family perception of Albinism shapes the personal identity of the participants.***

Two participants in the focus groups described the rejection that they had experienced from significant family members. One participant said that she didn't want to be an Albino. Goffman (1975) referred to this as shame because she perceived her Albinism as a negative thing to have. This shame was only evident in a participant who described significant rejection from family members. She had never experienced any acceptance because she had Albinism.

Participants who had experienced rejection from family members displayed greater levels of social anxiety and were more concerned about not being accepted. Participants who spoke about family acceptance explained that they felt normal and were less aware of their Albinism. They were socially confident and assertive.

**5.3.6 Schooling shapes the shared personal identity of the participants**

Learners that were in mainstream school reported that they were treated differently. Some reported bullying and some reported being treated special. Goffman (1975) reported that school is where the unaware person will learn about her stigmatic condition. This was contradicted at the special school. All

the participants said that the first time that they saw other Albinos outside their family was when they entered the special school. An array of emotions were expressed and participants expressed hope for security, friendships, an increased awareness of self and a sense of belonging because there were more number of people that lacked pigmentation. This demonstrates a self-identification with others who lack pigmentation (De la Rey, 1991). Identifying with others based on a lack of pigmentation was a new experience for the participants and represented a shift in mind-set. This shift in mind-set increased self-awareness, hope for safety, security and a better quality of life, better communication and easier socializing.

#### **5.3.7 Personal identity and social integration**

Participants differed in their perception of socializing with others. Some participants enjoyed socializing some avoided socializing and some only socialized with family. Variations in social preferences demonstrates that the participants have differing motivation to explore the broader social identity. Exploration of the social identity is an indication of the individual's sense of self that has been established within the family (Kroger, 2007). A sense of self is developed through secure family attachments (Marone, 1998). Participants with a higher alignment with 'normals' described an enmeshment with family (Scheff, 2007).

Participants who spoke of the difficulty in socializing also spoke of the rejection that they had experienced from significant family members. Thus the rejection of significant family members due to Albinism increased the participants' social isolation.

Some participants said that they would not readily socialize with strangers because they are apprehensive of whether the strangers would accept them. Fear of rejection from strangers demonstrates an integration of the social identity that has told the participants that they are not worthy of social acceptance (Goffman, 1975). Yet, these participants explained that they would always go to family functions or church as social functions demonstrating an absence of rejection from family members.

During identity development, teenagers individuate from their family and form social friends (Kroger, 2007). The participants all shared the same concerns with forming social friendships outside the special school. The common concern amongst the participants was that others want to use their Albinism for personal or social gains such as status. This creates feelings of alienation for the participants from some friends. The participants expressed feeling of belongingness with friends who make them forget about their Albinism.

Mature identity development depends on the resolution of the developmental stage of Autonomy vs Shame and Doubt. One participant demonstrated an unresolved stage of identity development due to Albinism.

Resolution of the group identity vs alienation crisis stage in identity formation was attained by most participants. It is easier to conform to the group identity when there is a larger number of Albinos because they are less alienated. Greater social acceptance is created when there is a larger number of Albinos in the social group. Social acceptance from the social group creates a sense of belonging for the participants.

The participant's attitude towards socializing was without regressive phenomenon. Some participants enjoyed socializing demonstrating a strong alignment with 'normals' (Goffman, 1975). Most participants preferred socializing with people who were familiar to them rather than meeting new people. Only one participant reported avoiding social situations completely.

Some participants demonstrated a level of assertiveness and social competence by explaining that they try to educate children so that they use the correct terminology and not prejudiced epithets. The participants still asserted themselves despite being exposed to stereotyping, prejudice and stigma. This reflects an adequate ego strength which was prevalent with most participants. Other participants said that they when they were younger that they wanted educate everyone about Albinism but now that they are older they have come to realize that people don't want to learn about Albinism

showing a maturation of social proficiency that has identity value. This is evidence of the resolve of the identity stage of Industry versus Inferiority (Kroger, 1993).

#### **5.4 ALBINO IDENTITY AS A GROUP IDENTITY**

Farhana Vally's Developmental Model of group identity specifies that parameters defining group boundaries must exist before a group identity can be delineated. A group identity exists if people comprising the group perceive themselves as sharing characteristics of the group (Wetherell, 1996). The participants reflected that they all do share characteristics of the group because they all share the medical condition of Albinism. This study has found that sharing the medical condition of Albinism has elicited interdependent processes from the social unconscious which has developed a shared personal identity amongst the participants. This shared personal identity constitutes a group identity based in Albinism. Albinism had meaning for all the participants because they all shared the same experiences with the social identity.

This study has found that a group identity does exist amongst teenaged participants with Albinism at a special school in KwaZulu-Natal. This group identity has clear delineating parameters that are meaningful to the participants. The group identity is based on shared aspects of Albino Identity but does not dominate the personal identity of the participants.

##### **5.4.1 Meaningful parameters of Albino Group Identity**

Badad et al. (1998) outlined criteria that must exist for the group identity to be meaningful. A meaningful group identity based in Albinism was observed in the participants according to the following criteria:

- Group boundaries were well defined according to Albinism.
- There is a recognisable "out" group from the participants who have Albinism.
- Group membership is exclusive and is based in strong socio identity ties.

- There is a struggle with an observable group.

**a. *Well defined group boundaries according to Albinism***

The boundaries of the group identity amongst the participants was defined by the social identity that perceived them as different. This difference excludes the participants from social acceptance in society (Goffman, 1975). The group identity is based on this difference which has excluded the participants from group membership. All the participants acknowledged that they were different from society because they do not conform to being 'black or white'.

The participants explained that the boundary of Albino Group Identity is delineated by the prominent visibility of the lack of pigmentation. The participants explained that others can see that they are not European and not the same colour as Africans. Thus the overt visibility of Albinism is a key factor in defining the boundary of Albino Group Identity as a minority identity group.

All the participants reported that they were responsible for drawing the attention of others. This group characteristic shows an acceptance that they possess something that captures the attention of others. This ability to capture the attention of others is what Goffman (1975) referred to as being "famed". The stigmatized person is "famed" (Goffman, 1975). Being "famed" leads to a lack of anonymity which is important to prevent people from making a nuisance of themselves. Goffman (1975) called this a restructuring of the interaction order because the "famed" person must learn to control her behaviour so that she can minimize the obtrusiveness of others. This was evident amongst the participants who all reported that they ignore people who behave poorly in reaction to the lack of pigmentation.

**b. *A recognisable "out" group***

The social identity of society are shared value systems that govern group membership (De la Rey, 1991). This study has found that skin colour is a

determining factor of group membership in society because it has meaning to the social identity. Being branded as different has separated the participants from the widespread social identity into a minority identity group. This label of difference informs the participants that they do not fit in with the social identity and that they are excluded from social acceptance (Goffman, 1975). The social identity governs group membership amongst the Albino participants through self-categorisation and identification with other Albinos. This was evident when the participants described seeing other Albinos for the first time. Thus, the social identity has created Albino Group Identity as a minority group based on the same kind of difference.

The participants describe others who have not accepted Albinism as a separate out group which the participants labelled as “people” or “they”. This “out” group consists of everyone who rejects Albinism or believes in myths that surround Albinism.

The participants show consensus in identifying the “out” group. The “out” group are distinguished by their behaviour and the manner in which they treat the participants. The “out” group are those people who will stare at the participants or point at them in public. “They” will invade the participant’s personal space to ask question, sometimes in English. “People” is a group that do not want to learn about Albinism but who prefer to believe in myths. The “out” group are those prejudiced people who yell insults at the participants.

### ***c. Group membership is exclusive***

Albino Group Identity has exclusive membership. The participants all alluded to the exclusivity of group membership because seeing other people with Albinism was significant to the participants. Goffman (1975) circumvents the topic when he said that the “famed” person find that there is no biography for her in the community. Yet, when Albinos are together, there is a biography for them as a group. Seeing other Albinos for the first time resonated strongly with the participants. The visibility of Albinism creates exclusive group



membership through self-identification. Perceiving that they could be part of a group because they have Albinism was initially shocking for the participants. Some participants said that it inspired hope for a better life. The better life would be without prejudice, threat and physical abuse because of having Albinism. All the participants said that being in a group with more Albinos increased social acceptance and created a sense of belonging and security for the participants.

Ironically, the participants do not limit those with Albinism to partaking in the group identity. The participants showed that any person who accepts Albinism can partake in Albino Group Identity. All participants showed that they were able to form friendships with normally pigmented people. All the participants reported that it was easier to form friendships with normally pigmented people when there was a large number of Albinos in the vicinity. The exclusivity of group membership for the participants consisted mostly of an exclusion of those who treated Albinos harshly or as superhuman. The “out” group does not need to see themselves as a group but are comprised of people that the participants perceive as excluded from their exclusive group membership.

***d. There is a struggle with an observable group***

The participant's lack of pigmentation creates a struggle that is based in colour, racial class and stereotyping. Participants described how other people would try to racially stereotype them into being European when they are Zulu. This struggle arose because the group mind holds traditional ideas of race and pigmentation. People try to class the participants into this stereotype which creates a struggle.

The struggle is created by the non-conformity of skin colour that others find intolerable. People react with hostility and prejudice to the participants because the colour of the participants does not conform to the social norm. None of the participants said that they challenged other people who believed in myths or openly refused to take the money that others offered them. Goffman (1975) explained this phenomenon that the stigmatised person

accepts his 'failure' and that she is accountable for managing the behaviour of others.

The belief that others have in myths creates a struggle for the participants. Myths are an important feature in the group identity because it creates a struggle with the social identity. People who believe in myths want to use the participants for their own benefit. This manipulation of the participants can range from an intrusion of personal space to sangomas who want to harm the Albino for use in muti. Jung (as cited in Snowden 2006) explained that myths were projections from the social unconscious. Yet, Erikson (1974) explained that identification with projections shapes identity development. The group identity of the participants, however, is not based in an identification with the myths but an individuation from others who believe in myths. This individuation has created a group strive for normality.

The group of participants exhibit an internal struggle through an identity crisis. Kroger (1993) explained that identity crisis during adolescence is a normal part of identity formation. The participants, however, shared a unique resolution in identity crisis that is based in colour, defining themselves as black in a white skin. Being black was associated with being African. Being white was associated with being European. The participants in different groups elaborated on the meaning of being a black in a white skin versus being white. This internal struggle was created by the social identity's pre-existing understanding of how a European should look and how an African should look. The resolution of an identity crisis based on colour is a struggle that is specific to Albino Group Identity.

The resolution of this identity crisis is seen when the participants all indicated that they were just like any other person. One participant articulated that she felt that she is the same like everyone else but that she is different only because others see her as being different. This resolution of normality coupled with the acceptance of being black in a white skin demonstrates mature identity formation and group identity. The participants, as a group,

have accepted that they each identify with the African race yet they each share a white skin. This resolve is core to Albino Group Identity.

#### **5.4.2 A group identity based in Albinism**

The fourth and final stage in Farhana Vally's Developmental Model of group identity is the delineation of a minority group identity. The group identity amongst the participants is based in shared aspects of Albino Identity. The boundaries of Albino Group Identity encompass aspects of Albino Identity as delineated by Blakenberg (2000):

- A spiritual delineation of Albino Identity
- Increased differentiation of the Albino
- Greater self-awareness in racial/cultural contexts
- Definitive impact of family reaction and participation in shaping Albino Identity
- Primary cultural and racial identification is with family

Albino Group Identity, however, contradicts the following aspects of Albino Identity:

- The family is not the only determinant of a sense of belonging, sense of community or sense of security because the group identity at the special school offered all the aspects
- Group identity also creates an increased awareness through self-identification
- The need for social acceptance is replaced by a sense of belonging from a group identity
- The differentiation of the Albino is decreased by a group identity that accepts the colour of Albinism as a group norm.
- Primary social identification is with other Albinism

The group identity amongst the participants developed through interdependent processes outlined by De la Rey (1991):

- Self-categorization amongst the participants as they relate to other Albinos
- Self-identification of the participants with other Albinos

- An increased sense of belonging at a special school with a large number of Albinos.
- Individuation from the social identity through a rejection of myths and a strive for normality

This fundamental group characteristic is based in the colour caused by Albinism. The colour of the participants due to a lack of pigmentation has formed the foundation of their shared group identity as a minority group. The label of difference has penetrated the shared personal identity of each participant and created a group identity. This group identity of being different due to Albinism comprise the basis of Albino Group Identity. Goffman (1975) called this a change in self-concept because she has an intimate awareness of how other perceive her. Thus, Albino Group Identity is seated in the colour of Albinism.

***a. Albinism shapes the group identity because it has meaning to the participants***

Albinism shapes the group identity because all the participants share characteristics that are pertinent to living without melanin. All the participants described that living without pigmentation in the skin creates more of a group identity than having no pigmentation in the hair or eyes.

A lack of pigmentation in the skin is more meaningful to the participants and contributes significantly to shaping Albino Group Identity. The lack of pigmentation contribute to the group identity of the participants by changing their daily routine and changing their dressing in the sun. The participants identify with each other because they share a social value system of trying to be protected from the sun. Protection from the sun is a necessary health issue but translated into a social issue for the teenaged participants because it changed their dressing and daily routine.

Albinism presents as a health issue and the participants are all aware that they need to take special precautions and tend to their skin. Taking special care of their skin is a characteristic of the group identity.

In order to protect their skin the participants all dress in the same way when spending time in the sun. The participants described using large hats, sunglasses and long sleeves when their cousins and sisters are dressed in shorts and t-shirts. This is meaningful for the teenaged participants because it characterizes the group identity. The participants share this commonality as a group norm. The way that teenagers dress is usually so that they can fit in with peers. Dress is a method of identification with a peer group. The acceptance that Albinism changes their dress code shows mature identity formation amongst the teenaged participants.

***b. Social norms exist for Albino Group Identity***

Amongst the participants social group norms exist that are specific for the participants with Albinism:

- As shared difference
- Drawing the attention of others in public
- Daily health care surrounds protecting their skin from the sun
- Dressing to protect themselves from the sun
- The colour created by a lack of pigmentation is a group norm
- 'Being black in a white skin' is a resolution of identity crisis.
- Families are overprotective when participants venture outside due to the social identity
- A lack of anonymity in public
- A reconstitution of behaviour to compensate for the curiosity and obtrusiveness of others

These social norms relate specifically to Albino Group Identity and are evidence of a minority group identity that is separate from the social identity.

## 5.5 CONCLUSION

The social identity has created psycho-social constructs that has changed the personal and group identity of the participants. This study corroborates aspects of Goffman's (1975) theory of Spoilt Identity which states that the social identity changes the personal identity of individuals thus creating stigmatization and informs that person of their stigmatic status. The way that the social identity changed the personal identity of the participants with Albinism informs objective one of the study. Goffman (1975) identified several social constructs of social identity that shapes the personal identity of the stigmatized person. These social constructs informed objective three of this study. Several differences from Goffman's (1975) theory also arose from the findings and psycho-social group framework. Goffman (1975) wrote explicitly of the social alienation of the stigmatised person. In this study it was found that although the participants were stigmatised by the social identity, the group identity amongst the Albino participants created a sense of belonging. This contradiction of Goffman's (1975) theory essentially relates the way that participants with Albinism have created a community through a group identity.

Aspects of Blakenberg's (2000) research has been corroborated and exists as a group identity although the group identity changed some aspects of the personal identity. The group identity creates a sense of belonging, community and security for the participants independent of the family, as Blakenberg (2000) had found. Ngidi (2005) autobiography was supported by this research in that the colour of Albinism has identity value. This was elaborated by this study because Albinism has identity value for a group of Albinos that has been created by colour.

A summary of how Chapter Two (Literature Review) relates to Chapter 4 (Findings) is outlined in figure 4 below. The theoretical model that evolved from this study is illustrated as Farhana Vally's Developmental Model of Group Identity. The theory is clearly correlated to the results, stipulating categorical groupings that underpin Albino Group Identity.

## **CHAPTER 6: CONCLUSION**

### **6.1 CONCLUSION**

Blakenberg's (2000) explanation that Albino Identity is created by the widespread social identity because of the colour of Albinism is corroborated in this study. The way that the social identity has created Albino Identity and Albino Group Identity is:

- Through a shared collective unconscious which holds the social norm of pigmentation.
- Through social interaction which is based in prejudices and racial stereotyping of the lack of pigmentation.
- Through the group mind which holds traditions and myths about Albinism

Albino Identity and Albino Group Identity is created through instinctive reactions of other people. A participant articulated that people don't know about Albinism but it's a choice because people don't want to know about Albinism. This points to an unadaptable group mind that shares beliefs and ideas about Albinism. It is the group mind that informs ideas to the individual and governs changes in behaviour from the individual in reaction to Albinism (Dalal, 2002).

### **6.2 MAIN FINDINGS**

This study intended to explore the Albino Identity of teenaged girls with Albinism in order to find out if a group identity existed that is based in their medical condition. Exploring the parameters that distinguish Albino Identity found that the shared personal identity of the participants constitute a group identity based in Albinism amongst the teenaged participants with Albinism at a special school in KwaZulu-Natal. This group identity has been shaped by the social identity of society.

This study has found that the reason that Albino Group Identity exists is because the social identity has shaped the personal identity of each participant with Albinism in the same. The primary factor in shaping the

personal identity of each participant was the colour created by their lack of pigmentation. The social identity has differentiated the Albino participants from society and given them each a label of different. The personal identity of each participant has accepted the label of different. The group identity of the participants is seated in a shared personal identity that is based on the label of difference. Thus the label of difference informed Objective 1 by showing that the social identity shaped the personal identity of the participants because of the colour created by Albinism. The social identity shaped the personal identity of the participants through social experiences with strangers which informed Objective 2. Social interaction with social constructs like family, peers and schools was also shaped by the social identity, thus informing Objective 3. Together these created the psycho-social reality of the participants which informed Objective 4 of the study.

Participants are excluded from belonging to African groups socially because of their skin colour. The social identity of society has separated the participants and labelled them as an “out” group that is excluded from social acceptance. The participants themselves have accepted the exclusion from social acceptance from society and have found acceptance in the special school where there is a greater number of Albinos. The participants have found a community that is independent of family in the shared group identity at the special school. Group membership to Albino Group Identity is exclusive and is based in the social acceptance of Albinism. All the participants indicated that being around a larger number of Albinos has given them more opportunity for social relationships. A large number of Albinos in the social group changes the norm of the group. There is a greater sense of belonging, more chance of forming real friendships and security.

The social identity has shaped the group identity and personal identity of the participants through the collective unconscious which presents as myths, racial stereotyping and prejudice. The findings of this study have shown that the social identity of society has created a shared group identity amongst the teenaged girls with Albinism through creating a social interaction based on stigma, prejudice and stereotyping. All the participants demonstrated a similar



pattern of reconstitution their behaviour to limit the obtrusiveness of other people. The shared aspects of group identity did not dominate the participant's personal identity completely because participants had added different meaning to their difference. This is an indication that regressive phenomenon is absent amongst the participants.

The group identity of the participants was shaped by the mythical beliefs of others. Myths encountered by the participants contained several archetypes. In Albinism two of these archetypes were identified namely the archetypal healer and the archetypal magician. All the participants reproved the myths that were imposed on them which lead to a group identity that was based in striving for normality. Racial stereotyping has created an identity crisis for the teenaged participants based in colour. Participants showed a resolution of this identity crisis through identifying themselves as 'black in a white skin'. The prejudice of others were meaningless to the participants and all the participants said that they just ignored those people, describing them as ignorant. These aspects exist because the participants are stigmatised by the social identity due to their inability to conform to societal norms. The visibility of their contravention of social norms is important for the participants and shapes Albino Group Identity. The lack of pigmentation in the skin is more meaningful to the participants than in the hair and eyes. Albino Group Identity had group norms which were observed by the participants.

Albinism does affect family dynamics. Most of the participants described the criteria of acceptance or rejection of Albinism by significant family members. The role of the family in developing Albino Group Identity is more significant to the participants than the opinion of society. All the participants indicated having attachment relationships with significant family members from a young age. Yet, families behaving overprotectively is also common to all the participants and contribute to their shared group identity. The participants identified several reasons that their families were overprotective namely fear of the sun, the derogatory names that others call them and because others would want to do them harm or use them for muti due to mythical beliefs that

surrounds Albinism. This is an indication that the family of the participants share a courtesy stigma from the social identity.

Resolution of the psychosocial stages of identity development leads to mature identity formation in adolescence. Some of the participants demonstrated mature identity formation and one showed a rejection of her Albinism indicating that the resolution of the stage of Shame/ Doubt had not been resolved. This participant had explained that her Albinism had been rejected by significant family members and that she did not feel a sense of belonging with family. All the other participants described an acceptance of Albinism among with family members as discussions of jokes around Albinism that is independent of myths, prejudice or stereotyping, intellectual knowledge of Albinism and feelings of normality.

### **6.3 STUDY LIMITATIONS**

The focus groups that were conducted at school premises had proven to be a suitable data gathering tool and it yielded sufficient data to inform the aim and objectives of the study. Some constraints on the time available did, however, constrain the researcher. The focus groups were conducted at a time that was convenient for the educators and learners and did not affect their academic programme. Any learner that was absent on the day of the interviews was automatically excluded from the focus groups.

Qualitative research limits the generalization of the study larger populations as an inherent limitation. Focus on female teenagers was to the exclusion of male participants. The framework of this study focused on the psycho-social group and overlooking ethnicity, racialization of African identity, black consciousness and disability identity.

Interviews with parents of the participants would have given this study deeper insights into how Albinism is perceived amongst the family and the way that Albinism has impacted on the personal development of the participants identities. This study reports only what is perceived by the participant with Albinism. The social identity of society is therefore reported from the

participants' perspective and what they understand of the mind of other people. The behaviour of other people is not recorded from the person enacting the behaviour but from the participant who receives the behaviour and integrated it.

#### **6.4 SIGNIFICANCE OF STUDY**

This study has corroborated Goffman's theory that the stigmatization of the social identity brands the individual with a difference as separate from 'normals'. Yet, this study has taken the separation of the stigmatized person one step further by uncovering that a group separated from mainstream society for the same reason can form a minority group with a shared identity that offers acceptance and a sense of belonging. The significance of the group identity of a minority group was overlooked by Goffman.

Previous research with participants with Albinism all focused on individual interviews which had confirmed the stigmatisation of those with Albinism and the way that they use various defence mechanisms. This study has changed the perspective of the isolated Albino to examining people with Albinism living in a group of Albinos as a special school. Those with Albinism living in a community with other Albinos are more socially integrated, have a higher level of acceptance of themselves and a greater sense of belonging at the special school.

The findings of this study can be used effectively in therapy to help those with Albinism exhibiting maladaptive or violent behaviour. An adjustment of group therapy to account for identity issues based in Albinism can enhance therapy with Albino learners to improve adaptive behaviour and reduce aggression.

The Developmental Model of Group Identity has research and academic value for those wanting to learn about group therapy. The emergence of this model from theory can assist in training group therapist.

Blakenberg's (2000) study delineated Albino Identity as a separate personal identity based on racial and ethnic isolation. This study corroborates

Blakenberg's study showing that Albino Identity does exist as a personal identity but conflicts the concept of Albino Identity being an isolated an lonely identity path. Albino Identity can be a shared group identity that offers its group members support, social acceptance and security from harm.

## **6.5 RECOMMENDATIONS**

Further research in Albino Group Identity is needed to corroborate or disprove this study. Research amongst male participants could draw similarities and differences between male and female participants to unpack the impact of gender based differences on Albino Group Identity. Research amongst the family members of those with Albinism could give deeper insights into how Albinism affects the development of Albino Group Identity through social integration in the home.

Farhana Vally's Developmental Model of Group Identity has valuable implications namely:

- Contributes to the theoretical knowledge base of Group Analysis
- Useful reference tool for group therapists
- Highlights the importance of group structure in creating a sense of belonging
- Sense of belonging and acceptance improves therapeutic value of group therapy
- Can assist in addressing identity issues in group therapy
- Establishing group norms can lead to conformity of group members
- Can facilitate acceptable behaviour in group therapy as a valued group member
- Can deal with issues of the social identity and personal identity
- Acceptance within group therapy context is valuable

Farhana Vally's Developmental Model of Group Identity can be tested in other circumstances for possible future research. Possible publications in research journals can also be explored.

## 6.6 SUMMARY OF CHAPTER SIX

This study set out to explore the plausibility of a group identity existing amongst teenaged girls with Albinism at a special school in KwaZulu-Natal. It has been found that a group identity does exist amongst teenaged girls with Albinism at a special school in KwaZulu-Natal. Albino Group Identity exist with the following factors that have been informed by the social identity:

- The differentiation of the Albino from society
- The label of difference is given to the participants based on their colour due to a lack of pigmentation
- The visibility of Albinism is an important parameter of Albino Group Identity.
- The skin has more identity value than a lack of pigmentation in the hair and eyes
- The way that family treat the participants is more meaningful for identity value than the way that society treats the participants
- The social identity makes the family overprotective
- Participants whose family has accepted Albinism have more mature identity formation.
- The social identity creates social interaction around myths, prejudice, stigma and stereotyping

Albino Group Identity is a minority group identity that exists based on the medical condition of Albinism. Albino Group Identity has the specific group norms that guide behaviour of group members, and serves to create a community where the participants belong outside of the family. The social identity creates Albino Group Identity through the collective unconscious and group mind. Social interaction changes the personal identity of each participants in the same way through social constructs and social experiences.

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# **APPENDICES**

## APPENDIX A: PROPOSAL PRESENTED AT OT DEPARTMENT

### Discipline of Occupational Therapy

### School of Health Sciences

Postal Address: Private Bag X54001, Durban, 4000, South Africa

Telephone: 031 260 7402

Facsimile: 031 260 7227

Email: [gurayaht@ukzn.ac.za](mailto:gurayaht@ukzn.ac.za)



UNIVERSITY OF  
KWAZULU-NATAL

INYUVESI  
YAKWAZULU-NATAL

24-10-2012

Dear Phindile

### Re: Research Proposals - Master of Philosophy in Group Therapy

This letter hereby serves to confirm that student: Vally, F (211540272), has presented her research proposal to academic staff and post grad students in the Occupational Therapy Department.

Thank you

A handwritten signature in black ink, appearing to read 'Thev Gurayah', written over a dotted line.

**Thev Gurayah**

Lecturer

Department of Occupational Therapy

Westville campus

University of Kwazulu Natal

Private Bag X54001

Durban

Fax: 031- 2607227

Tel: 031-2607402

e mail: [gurayaht@ukzn.ac.za](mailto:gurayaht@ukzn.ac.za)

## APPENDIX B: BRECS ETHICAL APPROVAL



18 September 2013

Mrs Farhana Vally (211540272)  
School of Health Sciences  
Westville Campus

Protocol reference number: HSS/0432/013M  
Project title: Albino identity amongst a group of teenage girls

Dear Mrs Vally


**Expedited Approval**

I wish to inform you that your application has been granted Full Approval.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the discipline/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

  
.....  
Dr Shenuka Singh (Chair)

/ms

cc Supervisor: Andrea Zank  
cc Academic Leader Research: Professor J van Heerden  
cc School Administrator: Ms P Nene

Humanities & Social Sciences Research Ethics Committee  
Dr Shenuka Singh (Acting Chair)  
Westville Campus, Govan Mbeki Building

Postal Address: Private Bag X54001, Durban, 4000, South Africa

Telephone: +27 (0)31 260 3587/8350/4557 Facsimile: +27 (0)31 260 4609 Email: ximbap@ukzn.ac.za / snymanm@ukzn.ac.za / mohunp@ukzn.ac.za  
Website: www.ukzn.ac.za

Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville

**INSPIRING GREATNESS**



## APPENDIX C: PERMISSION REQUESTED TO CONDUCT FOCUS GROUPS AT SCHOOL

Postnet suite 21

Private Bag x6

Cascades

3202

23 July 2014

The Principal

Mr D. C. Frank

87 Royston road

Mountain Rise

3201

Dear Mr Frank,

### Request for permission to run focus group with female learners at Arthur Blaxall School

Our conversation on 22 July 2014 has reference. I am currently doing my Master degree at UKZN and hereby request written permission to conduct focus groups with female learners with Albinism.

The aim of the study is to explore the group identity of female learners with Albinism. This requires an hour group discussion with female learners with Albinism. In order to minimize the disruption to the academic programme the time of the focus groups can be determined by yourself at a convenient time.

I thank you for your time, consideration and support. Looking forward to your positive response.

Sincerely



Farhana Vally

Occupational Therapist



# ARTHUR BLAXALL SCHOOL

Non Profit Organisation No.: 021-387-NPO



Tel.: (033) 3871400  
(033) 3871401 (Principal a/h)  
(033) 3871402 (Hostel)  
Fax: (033) 3872211/086-5288319  
e-mail: [blaxall@futurenet.co.za](mailto:blaxall@futurenet.co.za)

P.O. Box 8132  
Cumberwood, 3235  
87 Royston Road  
Mountain Rise  
Pietermaritzburg, 3201

Dear Parents,

Farhana Vally, an Occupational Therapist who is studying for her Masters Degree through UKZN, wishes to have a one hour group discussion with some high school learners who attend Arthur Blaxall School for the blind. The study wants to find out about the views of the learners.

General questions focusing on the learners lived experiences will be asked to the entire group. Learners will choose if and how they wish to respond. This discussion will be recorded on a voice recorder and will be transcribed into writing for easy use. The names of those participating in the group discussion will not be used and learners will not identified in any way. The learners are able to withdraw from this study at any point.

Their opinions will be respected at all times. Kindly complete the form below to give permission for your child to participate in this research discussion. Feel free to contact me on 0798811769 for any further information.

Thank you for your time and co operation.

Sincerely

Farhana Vally  
Occupational Therapist

**ARTHUR BLAXALL SCHOOL**  
PO BOX 8132 - CUMBERWOOD 3235  
PIETERMARITZBURG  
TEL 033 387 1400/1/2 - FAX 033 387 2211  
email: [blaxall@futurenet.co.za](mailto:blaxall@futurenet.co.za).

I, \_\_\_\_\_ (name of parent/ guardian), the (parent/guardian) of  
\_\_\_\_\_ (name of learner) hereby give my permission for her to participate in the  
focus group discussion. I understand that this discussion will be recorded and transcribed into writing  
without any learner being identified.

\_\_\_\_\_  
Signature of parent

\_\_\_\_\_  
Date

## APPENDIX E: SCHOOL POLICY ON TRANSFER OF GAURDIANSHIP



### ARTHUR BLAXALL SCHOOL

Non Profit Organisation No.: 021-387-NPO

Tel.: (033) 3871400  
(033) 3871401 (Principal a/h)  
(033) 3871402 (Hostel)  
Fax: (033) 3872211/086-5288319  
e-mail: [blaxall@futurenet.co.za](mailto:blaxall@futurenet.co.za)  
[www.ArthurBlaxallSchool.org.za](http://www.ArthurBlaxallSchool.org.za)

P.O. Box 8132  
Cumberwood, 3235  
87 Royston Road  
Mountain Rise  
Pietermaritzburg, 3201

3 February 2015


To whom it may concern,

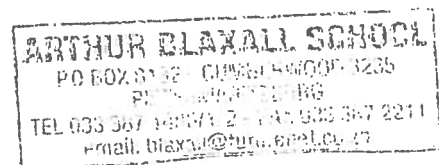
#### School policy on transfer of guardianship

I, Anusuyah Pillay, Acting Principal at Arthur Blaxall School, having been appointed on 01 January 2015, hereby state that it is school policy for all parents of hostel learners to transfer guardianship to the appointed school principal before learners are admitted to the hostel. The transfer of guardianship is via a signed Transfer of Guardianship and Indemnity Form which parents sign during registration of the school year.

I hereby declare that all parents of the learners that had participated in Farhana Vally's study on 09 May 2014 had transferred guardianship to the principal, Mr. D.C. Frank. These confidential forms are kept in the learners files, on school premises.

Faithfully Yours

  
\_\_\_\_\_  
Mrs. A. Pillay  
Acting Principal



# APPENDIX F: BLANKET CONSENT GIVEN BY SCHOOL PRINCIPAL



## ARTHUR BLAXALL SCHOOL

Formerly NEW HORIZON SCHOOL for the BLIND  
Non Profit Organisation No.: 021-387-NPO

**58 and LOOKING AHEAD**

Tel.: (033) 3871400  
(033) 3871401 (Principal a/h)  
(033) 3871402 (Hostel)  
Fax: (033) 3872211  
e-mail: [blaxall@futurenet.co.za](mailto:blaxall@futurenet.co.za)  
EMIS NUMBER: 103563

P.O. Box 8132  
Cumberwood, 3235  
87 Royston Road  
Mountain Rise  
Pietermaritzburg, 3201  
COMPONENT NO.: 060124

21 August 2013

Farhana Vally  
Postnet suite 21  
Private Bag x6  
Cascades  
3201

Dear Mrs Vally,

I have received your written request to conduct research at our school with learners with Albinism. I understand that you will be running three focus groups that will be last between 1-2 hours.

Permission is granted under the condition that the groups be run after school hours to prevent the disruption of learning.

I look forward to reading your dissertation as your finding may enhance the learning environment at the school.

Faithfully Yours

Desmond Frank  
Principal

*Desmond Frank* 02/09/13



## APPENDIX G: BLANK ASSENT FORM

### DECLARATION

I, \_\_\_\_\_ (name of learner) hereby acknowledge that I am willing to participate in a focus group that will be run by Farhana Vally. I understand that the nature of this group is a focus group discussion for research purposes. I have been given an information sheet containing her contact details and the details of her supervisor. I have been informed that this session will be recorded. I give my consent for the recording to be transcribed without me or my peers to be identified by name. I understand that my identity will be protected at all times and what I say will be recorded anonymously. It has been explained that I can withdraw from the study at any point without any negative consequences. I have been informed that the consequence of participating in this study is that my opinions and ideas will be recorded and documented and that unknown examiners will only be evaluating Farhana Vally at the University of Kwa Zulu Natal.

\_\_\_\_\_  
Signature of learner

\_\_\_\_\_  
Date

*Please feel free to contact us if you have any queries regarding the research*

*Sincere thanks from:*

Mrs Farhana Vally  
Occupational Therapist

Tel: 079 881 1769  
Email: fvally@vodamail.co.za

## APPENDIX H: FOCUS GROUP QUESTIONS

### Question Schedule for Focus Group

#### INTRODUCTION

The purpose of recording this discussion is to document what it is like to live with Albinism. Most people have only heard about Albinism and many people are curious. There is only one biography written by someone with Albinism and reading his book leave me with more questions than answers. I want to ask you questions about living with Albinism on record without naming anyone in this room. What you have said will be transcribed into written words for use in research purposes. You can choose not to say anything. Only my supervisor who works at the university in Durban will see the written transcription but she has never met anyone in this room and you will never meet her. The information will not be shared with anyone else but will be rewritten in my words to educate interested people on what it is like to live with Albinism.

This is a group discussion and what you say is voluntary. You don't have to respond if you do not want to say anything. If you are uncomfortable and want to leave that is an option available to you. There is no consequence if you leave. What you say is important for me and that is why I am recording it. I do ask that we do not use any names so that you cannot be identified. Afterwards, If you feel that you need counselling I will be available or the psychologist will be available as you prefer.

#### FOCUS GROUP QUESTIONS

- **What is it like to live with Albinism?** (Probe the difficulties caused by impaired vision and skin sensitivity compared to appearances, reaction/acceptance of others, alienation, living in the school hostel with so many others with Albinism vs community life)
- **Tell me about experiences that you have had with community members** (how is conflict handled, explore regressive phenomenon, is there an "us" v.s. "them" mentality, measure ego strength, explore inner dialogue and internalisation of supportive or traumatic group relationships)
- **How do you handle / react / think about it?**
- **What were your experiences at a mainstream school?**
- **What was it like to come into this school for the first time?**
- **How does it feel to be at a school where there are so many people with Albinism?**
- **What are your experiences if you are in a situation and meeting new people?**
- **What are your experiences in your community place of worship?**
- **What is it like to go out with friends?**
- **Describe your experiences within your family**—unpack comparisons with other albinos in the family or experiences as the only Albino in the family.

## APPENDIX J: BLANK TRANSFER OF GAURDIANSHIP FORMS

ARTHUR BLAXALL SCHOOL  
TRANSFER OF GUARDIANSHIP & INDEMNITY:  
HOSTEL LEARNERS  
ACADEMIC YEAR: 201\_\_\_\_\_

I, \_\_\_\_\_ [Full Name],

ID No of Parent: \_\_\_\_\_

of \_\_\_\_\_ [Address],

the Parent/Guardian of \_\_\_\_\_ [Child/Ward's full name],

ID No of Child/Ward \_\_\_\_\_

do hereby give the Principal of the abovementioned School guardianship rights over my child/ward during his/her residence at Arthur Blaxall Hostel at 87 Royston Road, Mountain Rise, Pietermaritzburg.

I fully understand and accept that all activities, while my child/ward is in residence shall be undertaken at my child's/ward's own risk. I undertake, on behalf of myself, my executors, my wife/my husband and my above-named child/ward to indemnify, hold harmless and absolve the Department of Education and Culture, KwaZulu-Natal Blind & Deaf Society, the Principal of the above-named School, his Staff, or any duly-appointed officer against and from any or all claims whatsoever that may arise in connection with any loss of or damage to the property or injury to the person of my above-named child/ward in the course of the child's stay in the School Hostel. The Principal, his Staff, or other duly-appointed officer will, nevertheless, take all reasonable precautions for the safety and welfare of my child/ward.

I also give the School Staff consent, though you will be fully notified and informed, of any emergency medical treatment that my child/ward would need [i.e. at Hospital/medical Practitioner] and in the event of substance abuse at School/Hostel to send my child/ward for a blood test, the results of which will be treated in the strictest confidence.

\_\_\_\_\_  
SIGNATURE OF PARENT/GUARDIAN

Signed at \_\_\_\_\_

this \_\_\_\_\_ day of \_\_\_\_\_ 20\_\_\_\_

WITNESSES:

1. \_\_\_\_\_

2. \_\_\_\_\_