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2018

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Young Men's Accounts of Living with Oculocutaneous Albinism in Relation to Identity and Masculinity

by

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Submitted to

the University of the Witwatersrand in partial

fulfilment of the requirements for

the degree of

Master's in Clinical Psychology

Supervised By: Prof Gillian Eagle

DECLARATION

This thesis is submitted in partial fulfilment of the requirements of the degree of Masters of Arts (Clinical Psychology). I declare that unless specifically indicated otherwise the following is the result of my own work.

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James van der Walt

January 2018

ABSTRACT

The current research arose from a particular interest in the ways in which different subgroups of men form and navigate their male identities and their masculinities. The decision to focus on the experiences of men living with oculocutaneous albinism stemmed from two inter-related premises: firstly, there is a dearth of research around this particular minority group; and secondly, there has been a call for the life experiences of this particular population to receive greater attention and understanding. Four participants were interviewed using a semi-structured interview schedule. The transcribed data gathered from these interviews was subject to a computer-aided thematic analysis. The findings of the current research suggest that the experiences of being stigmatized due to oculocutaneous albinism were highly injurious to the participants and lead them to internalize a strong sense of shame. This in turn affected the ways in which the participants experienced themselves in the world and interacted with others relationally, including in relation to friendships and more intimate partnerships. All of the participants feared that their albinism would make them less desirable to prospective life partners and were concerned that close others might be stigmatized by association with them. Their experiences appeared to influence the participants' positioning of themselves in relation to other men and were also implicated in the complex nature of their racial identity. Participants demonstrated a capacity to be reflective about their life experiences and about the responses of others towards them in respect of their condition.

ACKNOWLEDGEMENTS

Firstly, I would like to thank my supervisor, Prof Gillian Eagle, who gave me the best assistance and support anyone could ask for. She provided me invaluable guidance, not only with the current research, but also throughout my training as a clinical psychologist. She is not only a remarkable psychologist and academic but also the most kind and thoughtful human being.

I would like to thank my parents, Adriaan and Glynis, who spent countless hours helping me think about the research and also spent much time proofreading for t's not crossed and i's not dotted.

Thank you to the Serra family for being a home away from home and giving me a space to think and be cared for with so much love.

I would like to thank my friend and mentor, Prof Louise Stroud, for the constant support encouragement and faith in my development as a psychologist.

Thanks are also due to my sister, Alice, and to many of my friends for listening to my endless grumbles about the difficult nature of the training process. In particular, I thank a friend, Robyn Larkin, who, while also completing her Masters degree in photography linked to individuals with albinism, was a reliable sounding board for thoughts on the matter.

Lastly, I would like to thank the Witwatersrand Merit Bursary that allowed me the financial means to enroll and complete my training as a clinical psychologist.

Minorities become soft targets when it comes to prejudice. I am speaking about marginalized minorities. The lack of representation silences them, and makes them invisible in their society. It means they don't matter, their struggles don't matter. They'll inevitably be treated as almost human, but not quite. With our political history and our constitutional values, we cannot perpetuate exclusion and allow consequences of exclusion to fester. – Thanda Hopa (successful South African model living with albinism)

(P Andropoulous, 2017)

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CHAPTER 1

INTRODUCTION

1.1 AIMS AND OBJECTIVES

The current research was informed by a particular interest in the ways in which different subgroups of men engage with identity formation and masculinity. Given the lack of research in respect of persons living with the condition oculocutaneous albinism (hereafter referred to interchangeably as albinism) and observations that people with albinism face particular life challenges, this subgroup of men became the particular focus of the current study. Oculocutaneous albinism refers to an inherited condition characterised by a lack or a reduction of pigmentation in one's hair, skin and eyes (Gronskov, Ke and Nielsan, 2007; Laud, 2005). In conducting the research project, it became apparent that identity issues beyond that of gender identity were particularly salient for this group. Because of this reality, while still foregrounding considerations of masculinity where this was salient, identity formation more generally became a focus in the research project. Accordingly, the current research was concerned with exploring identity as constructed by young South African men with albinism. The research focused upon how men with this condition report that this has affected the formation of their identities as well as how they position themselves in regard to hegemonic constructions of masculinity.

The term identity has attracted different meanings and the concept has consequently been understood in numerous ways in research and existing literature (Schwartz,

2001). In this research paper, identity is understood to encompass an individual's goals, values, beliefs and their experiences of feeling part of a broader collective community (Vignoles, Shwartz & Luyckx, 2011). The same authors note that identity can be separated into two particular subcomponents, namely personal identity and cultural identity. An individual's internal understanding of his or her own goals, values and beliefs makes up such a person's personal identity while cultural identity is comprised of a person's experience of engaging with being part of a larger cultural or ethnic group (Umana-Taylor, 2011). One's own gender identity is regarded as a subcomponent of one's broader identity and carries both personal and cultural features. Identity and the term subjectivity are at times used interchangeably in social psychological literature. However, subjectivity is a useful term in carrying a slightly different meaning to identity (Hall, 2004). Subjectivity as a term refers to one's thoughts or reflections about identity and incorporates one's sense or feeling of carrying and living out aspects of identity. "Subjectivity as a critical concept invites us to consider the question of how and where identity arises… and to what extent we have any measure of influence and control over its development" (Hall, 2004, p.3-4).

Evidence suggests that in terms of gender and class, a hierarchy exists that places those that fall into particular identity categories as differentiated from and superior to others. In relation to gender and masculinity dominance has been associated with what has been termed hegemonic masculinity. Hegemonic masculinity is determined in different ways in different contexts (Connell, 2002). The performance of masculinity is rooted in current cultural ideals of masculinity, ideals that are context specific, and that are negotiated by many men in order to aspire to specific kinds of identity constructions

in part in order to maintain existing relations of dominance (Connell, 1987). Hegemonic masculinity as a cultural ideal is portrayed as follows:

> "The concept of hegemonic masculinity provides a way of explaining that though a number of masculinities co-exist, a particular version of masculinity holds sway, bestowing power and privilege on men who espouse it and claim it as their own" (Morrell, 1998, p. 608).

It is evident that men who do not easily fit into the idealized and dominant form of masculinity in a particular society need to find some way of positioning themselves in relation to such aspirational templates. Without over-anticipating what emerged from the study, based on existing literature, it appears plausible to assume that men who have albinism may find themselves marginalised by virtue of a number of features associated with their condition, as will be discussed further below. The current research accordingly aimed to explore how young men living with albinism view and establish their gender identity and how they position themselves in relation to their understanding of hegemonic masculinity.

With regard to young South African men living with the condition of oculocutaneous albinism the objectives of the current research were as follows:

1. To investigate the impact that living with albinism had on the identity formation and subjectivity of participants.

2. To explore how the participants' gender identity and masculinity, including how they position themselves in relation to the idea of what it means to be masculine in a hegemonic sense in South Africa at this time, was evidenced in selfdescriptions and narratives of identity.

1.2 RATIONALE

Existing research reveals that within sub-Saharan Africa persons with oculocutaneous albinism are faced with emotional as well as physical difficulties as they suffer from dermatological malignancies that are highly visible as well as other related conditions. More recently concerns surrounding the safety of individuals suffering from this condition have been highlighted as their body parts and blood are considered valuable for ritualistic purposes in some countries on the African continent (Cruz-Ingo, Ladizinski & Sethi, 2011). At the first ever South African conference held for people with albinism on 21 November 2014, the then Deputy Minister of Social Development Hendrietta Ipeleng Bogopane-Zulu (2014) stated, "As a nation it is about time that we join forces and talk about issues and the realities persons with albinism face. We need severe introspection on how we treat people with albinism in the country."
(South African Government News Agency).

Previous studies concluded that the prevalence of oculocutaneous albinism is greater in sub-Saharan African countries than in the rest of the world with a ratio of approximately one to every 3300 of the population (Kromberg & Jenkins, 1982). Although the prevalence of oculocutaneous albinism is higher in sub-Saharan Africa

than in other parts of the world the condition is evidently still relatively rare and those born with the condition represent a minority within the population. The participant group was specifically chosen for this study due to the fact that they form part of a vulnerable population group as their condition is associated with some debilitating features such as impaired vision and vulnerability to skin cancer. Their condition is highly visible and has lent itself to victimisation in some countries on the African continent due to myths and legends concerning those with oculocutaneous albinism as alluded to in the statement by the Deputy Minister of Social Development. Murugan (2014, p1.) notes that individuals living with albinism are “at times treated as outcasts or even killed for muti (traditional medicine).”

A study conducted by Pooe-Monyemore, Mavundla and Christianson (2012) notes the lack of psychological research conducted around individuals with oculocutaneous albinism, including research aiming to explore in a holistic way the life experiences of persons living with the condition. Another recent study considering the quality of life of individuals with albinism noted the vulnerability of the population group and the need for further research into their life experiences and identity related issues (Maai, Volpini, Santos & Rujula, 2015). The current research sought to engage with this knowledge gap by aiming to expand psychological investigation into identity related and experiential aspects of living with albinism. It is hoped that the research may play a role in addressing the dearth of knowledge around the psychological understanding of living with the condition of albinism, specifically as it pertains to identity formation and masculinity.

In addition to contributing to research into albinism and identity, the present research also aimed to contribute to the field of identity and masculinity studies in South Africa in particular by exploring how men with unusual, visible, identifying characteristics construct their identities and position themselves with regard to hegemonic masculinity. As the research into masculinity grows, so does the striving for equality between men and woman as well as between different groupings of men.

The research report is set out in a conventional manner with the subsequent chapter (chapter two) dealing with literature and existing research findings related to the research topic. Chapter three outlines the research approach adopted and chapter four presents the findings and discussion of findings, as is commonly the case in the presentation of qualitative research material. Chapter five, the final chapter, provides a brief summary of the key findings and an assessment of the strengths and limitations of the study.

CHAPTER 2

LITERATURE REVIEW

The literature review covers a range of conceptual and research- related material that is pertinent to the study, including considerations of identity formation and various salient aspects of social and personal identity. The latter includes a discussion of gender and masculinity, disability and racialised aspects of identity. It is recognized that the condensed coverage of each of these aspects of identity necessarily means that some of the complexities of each aspect of identity are not considered in any great detail. Nevertheless, it is hoped that the selective review of the literature will be sufficient to frame the study and its findings.

2.1 IDENTITY FORMATION

Eric Erikson was one of the first to consider human development in relation to a life span model, a model in which he included eight consecutive psychosocial stages of development. In each of these stages, an inherent crisis or conflict was advanced that every individual is required to encounter and resolve in order to proceed with healthy development (Erikson, 1968). The formation of identity is integral to this process and is foregrounded in the stage of adolescence. Erikson (1968) noted the following regarding his model:

> I shall present human growth from the point of view of the conflicts, inner and outer, which the vital personality weathers, re-emerging from each crisis with an increased sense of

> inner unity, with an increase in good judgement, and an increase in the capacity 'to do well' accordingly to his own standards and to the standards of those who are significant to him (p. 91-92).

Erikson (1968) maintained that the formation of identity has its roots in an early childhood process that begins with what he termed "identification" (p. 122). Identification refers to a child's tendency to identify and take on qualities of early attachment figures. Erikson noted, however, that one of the stages in his model, namely Identity Synthesis vs. Role Confusion, was the most fundamental psychosocial stage in relation to identity formation. This stage takes place primarily during one's adolescent years between the ages of 12 and 19. Erikson (1968) noted that at this stage an adolescent is required to gain a sense of self beyond that of the previous Identification with those around him or her – learning to both incorporate and separate from family and caretaker views of the self and associated values. This formation of a relatively coherent sense of self is to provide him or her with what is felt to be a solid place in the world. Being unsuccessful in the resolution of this crisis may lead to role confusion and cause difficulties in the person's understanding of his or her own personality characteristics and view of himself or herself and may warp the understanding of others' perceptions of the self (Bosman, 1994). Erikson proposed that while the developmental stages of his model are relatively fixed, identity development remains open to change and modification throughout adult life (Sokol, 2009).

Schwartz, Donnellan, Ravert, Luckyx and Zamboanga (2013) consider adolescence to be a highly significant time in identity development for individuals. The authors note

that factors such as one's familial, social, cultural and historical circumstances have a critical influence on the development of one's identity. Whitbourne, Sneed and Sayer (2009) agree with the premise that adolescence is important in identity development, noting that while identity formation is open to modification, adolescents and those in early adulthood are most amenable to being influenced and experiencing change in their identity. Current literature suggests that macro factors such as culture, gender role understanding, context and historical factors are vital to an individual's identity development (Burkitt, 2001; Lewis, 2003; Shwartz, 2001; Taylor & Oskay, 1995). As indicated previously cultural identity refers to an individual's sense of his or her own place in a larger cultural or ethnic group. Usborne and Taylor (2010) explain that the clarity of one's cultural identity lies in feelings of solidarity with various cultural or ethnic groups to which one is seen to belong. However, Bosma & Kunhen (2001 postulated that constraints in personal identity may be linked to the extent to which an individual identifies with a particular cultural system, arguing, for example, that an overidentification with a cultural system may, at times, constrain one's personal identity. "Successful" identity, however, may not be concerned with such kinds of constraints as Stryker (2003) notes that cultural or personal identity can both, even separately, serve the same function of grounding an individual in a set of social roles and responsibilities. Stryker (2003) advances further that the key to a healthy and positive identity formation lies in one's development of commitment to a particular set of values, attributes, and identification with such commitments. A significant part of one's identity can be located in one's gender identity (Stryker, 2003).

2.2 MASCULINITIES AND GENDER IDENTITY

For more than two decades, masculinity has been a focus of social-science research internationally. The subject has been proven to be multifaceted with authors within the literature advancing multiple theoretical points of view. Gender construction, including the study of masculinity and femininity, is a highly relevant field of research in contemporary society. According to Lanzieri and Hildebrandt (2011) masculinity/ies as socially constructed play/s a major role in determining different sociological, psychological and behavioural practices for men. A key notion concerning the socially constructed nature of gender identity relates to the observation that a hierarchical relationship appears to exist not only between men and women but also amongst different groups of men (Schefer, Stevens & Clowes, 2010). This notion will be considered in more detail below.

Gender roles began to be examined and researched in the late nineteenth century in relation to sex differences. For example, research was conducted at the time that lent itself to positioning women as subordinate based on their carrying inferior or problematic personality features and inadequate skills in certain areas (Connell, 1995). However, subsequent research on sex differences has shown little or no difference between men and women with regard to key psychological traits. What have been determined to be of importance are the ‘social role’ or ‘sex role’ differences between men and women. The notion of the ‘sex role’ talks to men and women being presented with expectations of how to be in the world (Connell, 1995). These sets of expectations are considered to be culturally specific (although overlapping across many parts and

cultures of the world) and are linked to ideas around what typifies and constitutes masculinity and femininity (Connell, 1995). Connell (1995, p.22) states that “sex roles are… the cultural elaborations of biological sex differences”.

Ryan (1990) maintains that the constitution of gender identity is a complex process where the mechanisms by means of which a person defines him or herself in this world are strongly influenced by their sense of being male or female and by their sexuality. He indicates that as a psychotherapist he has increasingly observed conflict and confusion, in varying degrees, concerning male clients’ sense of masculinity. Khan (2009) explains that “gender role models as a whole explore differences across men by examining social positions of men and by defining what characteristics men are expected to have in any culture to play the role of a ‘man’” (p. 52). Sherrod’s (1987) writing on gender identity further advances understandings of the way one learns one’s gender role and what is expected of males and females; “appropriate behaviour for males and females is heavily controlled by instructions” (p.218). Sherrod maintains that boys and girls are taught different ways to relate to the world by parents, peers, media and their teachers. It appears therefore that many writers in the field of gender and masculinity studies argue that gender identity is not the automatic product of a biological sex, but rather that it is socially constituted in relation to various external norms and inputs. There is also general consensus that the acquisition of a gendered identity is complex and that people’s lived experience of gender identity may reflect ongoing tensions and conflicts, partly with regard to alignment with cultural prescriptions and ideals.

David and Brannon (1976) created a model to capture the characteristics most commonly associated with masculinity, 'The Blueprint for Manhood', which despite being developed some forty years ago remains a commonly cited gender role model (Khan, 2009). This is a useful model to consider with regard to 'sex roles' and how these may play out for men. In this model, masculinity is broken down into four themes or constitutive elements, namely: '*No Sissy Stuff'*, '*Be a Big Wheel'*, '*The Sturdy Oak'* and '*Give em Hell'*, which serve as "benchmarks against which all men are measured" (Kimmel, 2003, as cited in Khan 2009, p. 55). Each of these clusters of characteristics relates to different aspects of masculinity such as competitiveness, stoicism and aggression propensity. Khan (2009) argues that the first theme '*No Sissy Stuff'* is the most influential of the four themes in defining masculine identity. He contends that this theme refers to the idea of a man figuring out how women are expected to behave and not doing the same, capturing the idea that masculinity is constituted in part in disidentification from the feminine. Kimmel then goes on to say that, "[t]his way of thinking reinforces the idea that people belong to separate groups" (in Khan, 2009, p.56). The theme '*No Sissy Stuff'* may emerge in the form of homophobia towards gay males and the marginalization of gay men and other more feminine identified men and is entrenched in the rejection of all attributes viewed as feminine or threatening to the construct of hegemonic masculinity (Kimmel, 2003, as cited in Khan, 2009). In addition, some of the other attributes point to the imperative for 'masculine men' to actively demonstrate potency and competitiveness - ideals that may be difficult to achieve for men from oppressed or marginalized groups.

Connell (1987) argues that different masculinities co-exist and that these are created and understood in relation to other masculinities and femininities. In subsequent research she develops this theme further by suggesting that within masculinities there exists a struggle for hegemony through processes of dominance and subordination of particular masculinities (or femininities) (Connell, 1992). The claim to authority marks hegemonic masculinity in a culturally acceptable form (Connell, 1995). Social context is an important factor to consider when identifying stereotypic or idealized masculinities and gender roles. According to Khan (2009), social context refers to the situationspecific and social realities that influence both how an individual interacts with others as well as how that individual views himself or herself in relation to perceived norms. In the predominantly patriarchal society of South Africa, it needs to be understood that superiority and power are still largely male associated (Ratele, 2012). This implies that male associated norms largely determine the value or worth of specific human attributes and behaviours (Khan, 2009). Khan (2009) contends that in order to maintain a system of patriarchy men will tend to act in ways that reinforce male privilege by conforming to the ideal version of masculinity, even if this is not in their personal best interests. In addition, different versions of masculinity will compete with one another for legitimacy and dominance. The political as well as socio-historical context influences the changing forms of masculinities and therefore 'preferred' constructions of masculinity will differ from context to context (Langa, 2008).

The main patterns, stances or positional possibilities of masculinity as proposed by Connell (1993) consist of what he termed hegemony, subordination, complicity and marginalization. These patterns form the structure by which masculinity can be

analysed. Connell uses these patterns to note that masculinity does not only subordinate women, but that there is a hierarchy of masculinities. Within masculinities amongst men, there exists an intergroup dynamic of domination and subordination; there are those that claim authority and those who cannot claim such authority. Thus, for example, heterosexual men tend to subordinate homosexual men and their values and lifestyle choices. There also exists a group (the complicit) that remains compliant and non-challenging of hegemonic precepts due to the benefits bestowed on them as a result of the system of patriarchy (Connell, 1993), as suggested earlier.

According to Morrell, Jewkes and Lindegger (2012) the concept of hegemonic masculinity has been widely used in South African research. They note in particular that it has been employed as a concept to compare different groups of men rather than explore men's dominance over women. Hegemonic masculinity, they note, has been used to explore power relations between men in relation to what may be considered the dominant group or groups of men. Mfecane (2008) develops this conclusion and notes that psychological research into masculinity has tended to focus on how men subordinate or marginalize other men and other masculinities in the hope of making them invisible. Furthermore, Morrell, Jewkes and Lindegger (2012) point out that South African research on masculinity has had a particular focus on violence and race, which appears to differentiate the South African literature from international literature on masculinity. Morrell (1994, 1998, 2001) employed the concept of hegemonic masculinity in research and proposed from the research findings that within South African context three dominant masculinity groupings exist, namely; black urban, rural African and white hegemonic. Both current and historical political developments have

been found to play a role in relation to the construction of masculinities and gender divisions in South Africa. Morrell, Jewkes and Lindegger (2012) mapped out some of the current politics in South Africa at the time of writing of the journal article and proposed some links between who held/holds political power and how masculinity is portrayed and understood in the country. They note that Jacob Zuma (the then and current president of the country) represents a rejection of thoughtful masculinity in favour of heterosexist, patriarchal and implicitly violent masculinity and that this expression of masculinity is justified in terms of "tradition". The authors further note that Julius Malema (the previous ANC Youth League President and the leader of the Economic Freedom Fighters) compounds this picture and tends to reinforce the promotion of such versions of masculinity. Zuma and Malema both successfully represent gender equality and thoughtful masculinity as anti-African (Morrell, Jewkes & Lindegger, 2012). The authors contend a need for recognition of multiple hegemonic masculinities in a South African context, a position informed by recognition of varying cultural ideas. They further advance that race is often viewed as a proxy for culture. While hegemonic masculinity shifts in accordance to context and culture, the following traits have been commonly named as markers for hegemonic masculinities: self-sufficiency; physical toughness and durability; aggression; being unemotional and uncomplaining; displaying sexual prowess; and risk-taking behaviour (Joseph & Lindegger, 2007; Langa & Eagle, 2007; Mcfecane, 2008). Davies and Eagle (2007) further note that providing for others is a more nuanced form of power that may be associated with hegemonic masculinity allowing for relations of control over women and children.

Connell (1995) acknowledges the importance of both the physical body and social processes in constituting masculinity and femininity and gender identifications. She notes that the physical nature of being a man or a woman is key to a cultural understanding of gender. It is through physical behaviour such as engagement in labour-intensive work and through physical appearance, such as roughness of one's skin and hardness of one's body, that a man is able to lay claim to his masculinity. According to Connell (1995, p.54) "the constitution of masculinity through bodily performance… means that gender is vulnerable when the performance cannot be sustained". However, constructivists argue that the social meanings attached to bodily features and displays are as important as embodiment per se. Salle and Harris (2011) elaborate this kind of perspective arguing in relation to gender that gender performance is not something that lies within an individual but rather is informed by institutional structures in critical ways. The constructivist literature suggests that meaning is inscribed into bodies, at least in part, by virtue of their perceived attributes and capacities. These meanings hold more power and symbolic understanding than just what an individual's body is capable or incapable of doing. Thus, as has come to be fairly and widely accepted, gender identity is located both within the physical and the bodily and within the cultural and interpretive, and the two realms are closely interrelated.

2.3 DISABILITY, MASCULINITY, IDENTITY FORMATION AND ALBINISM

Ethnographic fieldwork into the intersection between disability and identity gives weight to the premise that the world is centrally experienced through the body. The capacity of the bodies has configured and constrained individuals in significant ways (Staples 2011). Bodies are constrained by what they can and cannot do no matter whether they are abled or disabled and accordingly physical bodies matter in the construction of identity at both personal and social levels, including how particular aspects of appearance and physicality are socially constructed (Staples, 2011). Living with albinism entails living with a visibly different appearance and with associated disabilities as well as engaging with how these aspects of identity may be perceived and constructed by others. This can be linked to the notion that masculinity, the body and its performance, are connected in the construction of dominant and subordinated identity positions (Connell, 1995) as those living with disabilities may struggle to perform physically to the same extent that persons without disabilities can. This impacts on their positioning in relation to a hegemonic masculinity.

The British Social Model defines disability according to two tenets, namely impairment related to biological irregularities and the social penalties and consequences of a specific impairment. (Barnes, Mercer & Shakespeare, 1990). However, this understanding has been criticised due to its failure to acknowledge that impairments themselves are socially constructed and that one cannot entirely remove the consequences of bodily impairment from the physical body (Shuttleworth & Kasnitz, 2005). In relying on Shuttleworth and Kasnitz, constructivists have challenged the notion of disability attached to a medical model which tends to naturalise disability in

negative terminology and locates it entirely within an individual's body. They protest that the role of institutional power in constructing bodily experience is largely unacknowledged in such a version of disability (Staples, 2011).

Shuttleworth, Wedgwood and Wilson (2012) have found disability and masculinity to be in conflict with one another with disability being associated with a lack of agency and notions of helplessness while masculinity is considered to centre on being powerful and autonomous. The authors note that shifts have been made in understanding the relationship between the two social identities from a previously rather static position to one that incorporates a more dynamic understanding of the interaction (intersection) between the two aspects of identity. They also noted that cultural understandings of both the concept of disability as well as of masculinity further complicate theorization and research into the relationship between the two aspects of identity and selfhood and signal that writers and researchers should be careful of overgeneralization.

Ramanathan (2009) notes how bodies are 'languaged' in certain ways in relation to how they physically appear to the eye. This kind of 'languaging' is likely to hold true particularly strongly for individuals with albinism who present with markedly different physical features that are immediately recognizable to others. The same author contends that language is the mode through which one's "engagement with the world happen[s] but also [is] the medium through which our collective notions of disability and able bodies get discoursed into place" (p. 3). The cultural assumptions about the body, the meanings connected with physical difference and how persons with albinism identify with disability and terminology utilized around their disability, are all likely to

play into discourses and ideas around albinism and how it is understood in broader communities and by individuals, living with or without albinism, within those communities (Broco, 2015).

What has been noted in the literature is that labels assigned to those with albinism reveal that they are generally othered, suggesting that they are treated as fundamentally different at a community level in the sense that they are seen as 'not part of' or 'not the same as" (Broco, 2015). While there are labels and terms that may promote stigma that are utilised in relation to persons with albinism in communities, there are also attitudes of acceptance and inclusion. This reality must be noted and not be underestimated (Broco, 2015). As already emphasized above, specific kinds of impairments have different meanings depending on the context with in which they are located and albinism constitutes one such form of impairment (Staples, 2011).

It is apparent that identity formation and the social and personal construction of masculinities are interwoven. Furthermore, there is a complex relationship between the body and gender identity. Both an understanding that centres on the physical capacity of the body 'to do' or 'not do' as well as a symbolic and culturally informed understanding around what this means, are significant in thinking about living with disability. Disability is generally associated with non-hegemonic or subordinated forms of masculinity, in part because it diminishes the capacity to demonstrate potency. While one should be wary of equating albinism unproblematically with disability and devaluation, based on both theoretical argument and empirical observation the literature around masculinity suggests that there are inevitable difficulties entailed in

living with a condition which marks one as different, is clearly visible to others, and is associated with visual impairments and vulnerability to sun damage. While the reality of the condition of albinism is understood in different ways depending upon cultural location it has also been made apparent that there are some associations to albinism that may put those living with the condition in harm's way (Baker, Lund, Nyathi, & Taylor, 2013). It is these kinds of concerns that contributed to the interest of this research project. In addition to being associated with disability, the pigmented skin condition associated with albinism also carries resonances for aspects of racial identification, particularly in a country in which the majority of citizens are black (skinned) and in which many of those living with albinism come from what would commonly be understood as black African families. This contributes a further layer of complexity to identity formation and subjectivity for men living with the condition.

2.4 RACIAL IDENTITIES, STIGMA AND THE INTERNALIZATION OF SHAME

Racial identity is formed through a process of racial socialization which has been found to be predominantly influenced by family as a socializing agent (Stevenson, 1995). A positive racial socialization has been found to be linked to transmitted messages that endorse cultural pride and promote awareness of societal oppression as the cause of any feelings of inferiority (Stevenson & Bentley, 2007). Helms (1993) defines racial identity as "a sense of group or collective identity based on one's perception that he or she shares a common heritage with a particular racial group" (p3). In addition to socially defined categorisations, an individual's physical features also inform their racial identity (Stanley, 2014). In a study conducted by Phatoli, Bila & Ross

(2015) the authors focused on the difficulties that an individual with albinism may face as a result of being black-identified in a physically white body. The study concluded that the participants with albinism were comfortable with individuals with whom they were familiar and who they could reasonably expect to treat them well. However, it was found that the participants struggled to engage socially with strangers. It was postulated that this occurrence was linked to the various indicators and experiences of discrimination and stigma that the participants had previously experienced as a result of their condition and that this was in part related to their external “whiteness” in a predominantly black community.

Herek (2014), whose research concerns discrimination against individuals living with HIV, suggests that living in a stigmatized body tends to lead to individuals avoiding exposing their condition to avoid discrimination. Previous experiences of discrimination are linked to feelings of shame and it is then evident that people with such a history are likely to be avoidant of the possibility of having to revisit feeling scrutinized, ostracised and humiliated and are liable to become socially cautious (Herek, 2014). Shame plays a powerful role in the development of an individual’s self-concept as well as in the development of his or her levels of self-esteem. Morrison (1989) defines shame as an experience of not meeting what has been internalized as an ideal and carrying with it a range of difficult feelings. Tompkins (1962) used the term master affect when considering shame. He notes that shame is considered a master affect since shame has the possibility of strongly influencing the affect experiences of a person and of colouring other affects and aspects of engagement with the world. Scheff (1994) supports this contention of Tompkins in noting the potency of shame as an

emotion. While HIV and AIDSs related stigma may be related to certain kinds of changes in physical appearance, ARV treatment often arrests such changes, whereas for people living with albinism there is no escaping the manifestation of their condition. While the stigma associated with HIV and AIDS is linked in part to the possibility for contagion or transmission of the virus and this is not the case in instances of albinism it is apparent that both types of condition attract largely negative stereotypes that in turn contribute to shame in those who are affected by such conditions.

For many people living with marginalised, precarious or openly stigmatised identities numerous and repeated experiences of shaming as part of everyday life are experienced in a particularly negative manner which is likely to be internalized by the individual (Kaufman & Raphael, 1996). In order to consider this notion, one may refer to literature that talks to marginalized identities more generally and how previous studies have considered the internalization of shameful experiences. In an early, arguably seminal, study conducted in America by Clark and Clark (1939) it was concluded that the participants, consisting of young black children, had internalized historic and systemic negative treatment of black individuals in the United States and consequently sought to be white. Most participants appeared to have developed negative feelings towards being black. This early study introduced the idea that social stigma could become internalised by those who were the object of such stigmatization. In order to further develop the notion of the internalization of external negative reactions to the self, one may consider the notion of the internalization of homophobia by homosexual individuals. In a study conducted in Pretoria, South Africa, it was discovered that high levels of internalized homophobia existed in men who have had

sex with men (MSM) (Vu, Tun, Sheehy & Nel, 2012). The study authors concluded that there was a correlation between the degree of exposure that MSM had to stigma and homophobic experiences and their internalized homophobia (Vu, Tun, Sheehy & Nel, 2012) with increased exposure to expressed stigmatization directed towards homosexual men associated with increased internalized homophobia. Interestingly, a separate study into a similar topic noted that higher levels of education were found to be associated with decreased levels of internalized homophobia amongst gay men (Allen & Oelson, 1999). Brown & Trevethan (2010) found that there was a correlation between higher levels of education and access to intellectual and other kinds of informative resources, which they suggested offered the opportunity to critically reflect on sexual identity and the pejorative associations to same sex choice. Brown and Trevethan (2010) found that there was a link between internalized homophobia and feelings of shame. Other researchers have also noted that there is a complex relationship between shame, internalized homophobia and identity formation: “for at least certain (‘queer’) people, shame is simply the first, and remains a permanent, structuring fact of identity” (Sedgwick 2003, p.64). A study conducted by Mcdermott, Roen and Scourfield (2008) noted that homophobia may be managed by LGBT persons through shame-avoidance strategies, in turn counter-productively shutting down the potential for those individuals to engage with these difficulties beyond an individual level. This may reduce the potential for these individuals to seek support at national, institutional or community levels and to have the opportunity for disconfirming experiences. Again, while one cannot map the experiences of homosexual individuals neatly onto those living with albinism it is suggested that some of the same types of mechanisms may be operative in trying to negotiate a visible identity, associated with

disability and also bringing with it something of sense of strangeness or of something “queer”. The parallels seem apparent.

This brief review of theory and research related to the current study has indicated that identity and subjectivity are closely intertwined and stem from both personal and bodily manifestations and sociocultural constructions of aspects of appearance and group affiliation. It is argued that gender is a core aspect of identity and that for men part of their identity construction may stem from their positioning relative to what is considered to be hegemonic with regard to expressions of masculinity within the society in which they are living. Albinism is associated with a highly visible condition that marks individuals as different or distinct, particularly in black African communities. The condition of oculocutaneous albinism brings with it specific vulnerabilities, some of which have been associated with disability. There is evidence to suggest that disability and marginalization in terms of identity may contribute to specific kinds of struggles with regard to measuring up to hegemonic ideals of masculinity. It has also been suggested that carrying socially stigmatized identity features may contribute to shame and social withdrawal amongst individuals so identified. Together these features suggest that it may be useful to continue to explore the experiences of people living with albinism in South Africa, and in this instance of young men in particular. The research study was interested in gaining a deeper psychological understanding of what it has meant and continues to mean to live with the condition.

CHAPTER 3

METHODOLOGY

3.1 RESEARCH DESIGN

The current research falls under the qualitative umbrella of research methodology and was intended to be exploratory and descriptive in nature in order to investigate the kinds of questions posed. Qualitative research aims to understand phenomena in an in-depth manner that is specific to context (Golafshanio, 2003). This approach was considered suitable for the current research study as the aim was to develop an understanding of the construction of identity and masculinity amongst a specific grouping of men in the South African context, namely men with albinism.

The paradigm in which the current research was located included social constructionist and more realist related, interpretive elements, and in this respect, could be considered 'psychosocial'. Social constructionism is concerned with social processes and identity in context, including the use of language and how this creates the subjective realities and discourses that are central to life and experiences (Nightingale & Cromby, 1999). The current research used language based interview text as data in order make sense of the subjective realities of the participants involved, particularly their understanding of their identities and their masculinities, as well as how they view and position themselves with regard to this aspect of their identity. In addition, however, the interviews generated material about phenomenological and experiential aspects of living with albinism and these aspects of the data were treated as 'real' rather than

purely discursive and were subject to a more interpretive analysis. Thus, the overarching psychosocial approach to the data analysis includes reference to how albinism and masculinity appeared to be discursively constructed and the manner in which this was engaged with by the participants as well as consideration of experiential aspects that were looked at through a more clinically oriented interpretive lens.

3.2 RESEARCH QUESTIONS

The following research questions informed the study:

What impact did growing up with oculocutaneous albinism appear to have on the social and personal identities of young South African men living with the condition?

How do young South African men with oculocutaneous albinism experience their positioning in relation to hegemonic understandings of masculinity and what specific aspects of living with the condition appear to influence or shape their gender identity?

3.3 SAMPLING AND DATA COLLECTION

Purposive sampling was used in order to find participants to take part in individual interviews. Purposive sampling entails locating and selecting participants for a particular research study based on preselected criteria relevant to the research (Kothari, 2013). The criteria in the case of the current research were the following: participants had been diagnosed with the condition of oculocutaneous albinism,

participants identified as (biologically) male, participants were South African born and living in South Africa, participants were young adults falling in the age bracket of 18 to 30 years of age, and participants were sufficiently fluent in English to enable meaningful data to be generated that could be subject to analysis by an Englishspeaking researcher.

At the outset of the study, it was intended to conduct interviews with between six to eight participants. Prior to embarking on the study the disability rights unit at the University of the Witwatersrand was approached as a networking source and a site for placing pamphlets and posters in order to locate potential participants. A letter requesting such access was sent to the unit (Appendix A) and it was agreed to allow such indirect forms of recruitment. After several weeks it became apparent that this was not a fruitful approach for gaining participants for the research. However, having heard about the research topic fellow students and extended family members indicated that they knew of young men fitting the participant criteria who might be willing to take part in the research. With their agreement such individuals were then sent the participant information sheet (Appendix B) and were invited to take part in the study if they were interested in doing so. Five participants were accessed via this route, four of who agreed to take part in the study. Although it was hoped to use “snowball sampling” once the initial cohort of interviewees had been identified, in the sense of finding further participants through potential linkages between young men living with albinism (Neuman, 2006), this also did not prove to be fruitful. Interestingly it appeared that the initial participants did not generally have ongoing contact with other persons living with albinism. After several months of attempting to access further participants

it was evident that it was particularly challenging to source participants who were eligible as per the above criteria. Accordingly, interviews were conducted with four participants who presented as willing to participate in the project and follow up interviews were conducted with two of these four participants in order to add depth to the data. It was found that the interviews were rich in nature and accordingly it was decided that sufficient data had been collected from the four participants to allow for meaningful analysis and comment, bearing in mind that this was a research project of "limited scope".

3.4 SEMI-STRUCTURED INTERVIEW SCHEDULE

Semi-structured interviews were conducted in order to generate data from the responses and observations of the participants involved. In a qualitative interview, which generally involves a face-to-face interaction between an interviewer and a respondent, the interviewer has a general plan of inquiry and topics to be covered, but not a fixed set of questions that must be asked with particular words and in a particular order. The qualitative interviewer has to be fully familiar with the areas to be investigated and questions to be asked, which allows the interview to proceed smoothly and naturally (Babbie, 2011). Semi-structured interviews conducted on a one-on-one basis allowed participants to be engaged in responding to the somewhat sensitive inquiry and appeared to enhance the authenticity and depth of participation. The participants were telephonically contacted and a meeting was set up with each of them at the Emthonjeni Centre at the University of the Witwatersrand. In one instance the interview was conducted at U-Clin, a psychology clinic at Nelson Mandela University

in Port Elizabeth. Each interview was approximately one hour and was conducted by the current researcher. The present research relied on a self-generated interview schedule or set of prompts that was designed to draw out themes around living with albinism and more particularly around masculinity and how the participants experience/d their condition in relation to their gender identity (see Appendix C). Although the initial focus of the study was primarily on masculinity and gender- related aspects of identity, during the semi-structured interviews it was found that the participants reflected at length on identify formation more broadly, including on aspects of their developmental history. Interviews were opened with the broad open-ended question: “Tell me what it is like to live as a young man with albinism in South Africa – I am interested in hearing about your thoughts and experiences.” Depending on what aspects were emphasized in response to this question various other areas of life experience were probed in relation to issues that were identified as significant by the participants and with regard to the research aims and objectives. Following transcription of the first four interviews it was decided that it would be productive to approach two of the participants for follow up interviews as it seemed that there was potential to generate an enriched understanding of aspects of the data. Both participants had indicated their willingness to continue discussing the material that formed the focus of the study and were highly engaged in the interview process. The transcripts used to generate data in the current research are available upon request to the examiner/s of the research.

The table below shows some of the relevant demographic information of the participants interviewed and is provided in order to give some sense of the nature of the group from whom the data was derived.

Demographics of Participants				
	Participant 1	Participant 2	Participant 3	Participant 4
Age	23	28	30	23
Race	Black	Black	Black	Black
Highest Level of Education	Matric (enrolled in tertiary studies)	Tertiary degree	Matric	Matric (enrolled in tertiary studies)
Relationship Status	In a committed relationship	Married	Single	In a committed relationship
Number of Interviews	Two	One	One	Two

3.5 METHOD OF DATA ANALYSIS

Transcripts of the interviews were completed and formed the corpus of data for interpretation and generation of findings. Analysis and reporting of the data were conducted using Braun and Clarke's (2006) model for conducting thematic analysis as a guide. These authors propose a six-phase process that entails:

- familiarizing yourself with the data,
- generating initial codes,
- searching for themes,
- reviewing themes,
- defining and naming themes and
- producing the report.

The themes emerging from the research were generated from several readings of the transcripts and subsequent coding of material into initial themes and then refinement of these themes as per Braun and Clarke (2006). Both I and my supervisor read the transcripts and generated themes independently. These were then discussed and due consideration was given to points of similarity and difference. Ultimately, seven core themes were identified. These themes are elaborated upon in detail in the Findings and Discussion chapter that follows.

As far as possible rigour in the analysis process was maintained by following Guba's model of trustworthiness as outlined in Shenton (2004):

- To ensure credibility the findings must be congruent with the participant's experience of reality. This will hopefully be evident in the presentation and discussion of the findings and the efforts made to present participants' experiences as they were conveyed.

- Transferability is made possible through the provision of background data to establish the context of the study and detailed description of the phenomenon in question to allow comparisons to be made. Thus, the rationale and method for conducting the study and process informing the data analysis have been clearly elaborated.

- Dependability is generated through the use of overlapping methods of data collection and inquiry and by providing operational details with regards to the design and implementation of the inquiry and its execution. In this instance the follow up interviews allowed for some consolidation of material and for questions to be posed around issues that were unclear but beyond this there was no further element of data collection. However, data from the individual interviews were triangulated and cross-referenced with observations made around and during the interviews.

- Confirmability is aimed for to help ensure as far as possible that the findings reflect the experiences and ideas of the informants, rather than the characteristics and preferences of the researcher. Confirmability in this instance was aided by engagement in a reflexive process and by the supervisor serving as a cointerpreter of thematic material. In addition, as is desirable in qualitative research the presentation and the discussion of findings include several direct quotations from the interviews so as to embed the analysis in what was volunteered by the participants themselves. Since the interviews had been audio-recorded, the articulations were accurately captured, which is in accordance with recommended protocol (Shenton, 2004).

The analysis was conducted in a respectful manner with the hope of providing a rich and deep understanding of the participants' experiences of being men with oculocutaneous albinism in a South African context and how, if at all, this appears to play a role in how they position themselves in relation to hegemonic masculinity.

3.6 REFLEXIVITY CONSIDERATIONS

Sensitivity to various differences between me, as the researcher, and the participants was cultivated at all phases of the research process. These differences included cultural, physiological and sexual orientation differences, amongst others, and it was understood that this might play into my own understanding of the data and of representations of aspects of identity and masculinity. This dimension of the research

process is reflected upon at some length in the Self-Reflection sub-section towards the end of this research report.

3.7 ETHICAL CONSIDERATIONS

Ethics remain a cornerstone to Psychology as a profession, including in the conducting of research, and ethical principles and practices were strictly adhered to in the execution of the project. The research proposal underpinning the research project was subject of an ethical screening process within the university and consent to conduct the study under Research Ethics Protocol Number H16/05/26 was obtained.
Some of the considerations specific to the project are outlined below.

Anonymity could not be assured as the researcher met the participants and their interviews formed the data of the research. However, a process whereby the researcher creates confidentiality was observed in that any publically identifying features were removed from the participants' interview transcripts and the research report and confidentiality in this regard will also be assured in any further publication that may result from the research. It is acknowledged that the participants will be identifiable to themselves in the write up of the research and the findings are therefore written up with this consideration in mind. It was made apparent in the informed consent sheet that direct quotations would be used in the write up of the research.

Informed consent (appendices D and E) was obtained from all the participants before the interviews were conducted and the participants were informed that they had the

right to discontinue with their involvement in the research at any stage. Participants received no remuneration for their involvement in the study.

The need to be mindful not to perpetuate racial stereotypes was borne in mind in writing up the material. For example, I was aware that the nature of myths and legends around individuals with oculocutaneous albinism could be viewed as contributing to problematic racial categorizations and stereotypes with associations to 'muti' and the primitive in African culture. The material has thus been written up with consideration of such associations. However, it should also be noted that while these myths and legends exist predominantly in other African countries, most notably Tanzania and Malawi, they have been identified as existing in South Africa as well. This situation may place those living with albinism in a vulnerable position and therefore their safety and dignity had to be carefully considered with regard to the places where the interviews were conducted, the questions that were asked and the manner in which the material was eventually presented in a written format.

It was also necessary to remain aware of the fact that those living with albinism may fall within the category of 'individuals with disability', although people living with the condition may not necessarily choose to think of themselves in this way. This issue was thought about in relation to the possible vulnerability of the population group and was held in mind during the research process.

While it did not prove necessary it was also borne in mind that being interviewed about their condition might unearth discomforting or even traumatic memories and associated feelings amongst participants, and that should this be the case accessible and affordable counseling resources might need to be made available to them.

Participants were all briefly debriefed about their experiences of the interview/s at the end of each interviewing session. It will be apparent from some of the quotations included in the subsequent chapter that all of the participants did proffer sensitive material and that distressing interactions were commonly described. However, none of the participants felt any need to pursue professional counseling and all of them volunteered that the discussion had felt helpful, supportive and productive. Participants also indicated that they placed value upon the research endeavor and wished that the experiences of people living with albinism could be more widely appreciated and shared.

3.8 DISSEMINATION OF RESULTS

In terms of dissemination of the results, a copy of research report will be available through the University of the Witwatersrand library portal after the examination process. In cases in which this was requested participants will be provided access to a summary of the findings of the study post the examination of the research report. Should the opportunity arise and the findings warrant this, the research findings may be presented at a conference and/or a journal article may be submitted for publication

CHAPTER 4

FINDINGS AND DISCUSSION

This following chapter seeks to document and analyse the data emerging from the interviews conducted with the four participants, young black South African men living with oculocutaneous albinism. The themes identified as salient in the analysis and explicated in the current chapter are as follows: Stigma and Being Othered; Visibility in Public Spaces; Internalization of Shame and Self-doubt and Self-protective Measures; Relationships with Intimate Partners and Contamination by Association; Comfort in my Skin; and Racial Identity. Headings will be used to delineate these themes and quotations taken from the interviews will be used to illustrate the thematic analysis.

4.1 STIGMA AND BEING OTHERED

A process of both being stigmatized in reality and perceiving themselves as stigmatized played out in the lives of the participants. There was a pattern of early experiences where the participants felt stigmatized within a range of settings and the sense of being associated with stigma seems to have carried through to adulthood within all of the participants' lives to date in various areas, with greater or lesser severity at different times during their development. This section seeks to explore this process of stigmatization by mapping out the participants' reported experiences and how these appear to have become internalized, exploring how all four of the participants live with

a frequent sense of shame linked to their condition. Following this discussion various subthemes will be unpacked that appeared to be related to this process of

internalization of being stigmatised.

In order to develop this section it is necessary to describe some developmental experiences of the participants. While the sub-sections are clearly inter-related in some respects, for the sake of clarity the use of subheadings will be employed to delineate key areas of interest.

As children, all the participants experienced teasing that was linked to the oculocutaneous albinism they were born with. Participants recounted some of the names they had been called when being teased:

> *Particpant 2: I think the most I can remember or the word I can associate is snake, but was from a kid at school… a lot of animal sort of names with albino in front of it.*

> *Participant 1: Yeah, Inkawu which means a monkey.*

The experience of being compared to something that was not human, be this an animal or a plant or an object, was common amongst the four participants. Two of the participants experienced being compared to an animal and one had the feeling that he was treated as if he were less than human. The sense of carrying a dehumanized identity was evidenced by Participant 4 who said:

"*I feel sad about that, the fact that humanity will treat you like you are a plant or something*".

What comes to mind in relation to this quotation is the view that the participant has experienced himself as a specimen rather than a human being; that there was a curiosity around his being and his body that objectified him – "*like a plant*". In the quotations there is some indication of a hierarchy being created as other children feel free to comment freely and negatively on the participants as appearing different and therefore being constructed as objects of curiosity and with pejorative connotations. The process reflected here is that the participants as young children were subordinated, placed lower down on the hierarchy in the classroom and lower down on the 'food chain' so to speak. The quotations above reveal the manner in which the participants' bodies are 'languaged' and the negative discourses that are accordingly created about them. This is in line with literature that denotes that bodies that are visibly different to the eye often are 'languaged' in ways that disempower or denigrate them (Ramathan, 2009).

One must consider how the participants were othered when they were young boys. The consequence of being visibly different and the impact this had on the participants' engagement with those around them was apparent in a significant portion of the content brought up during the interviewing process. From a young age the participants were compelled to feel different around their peers:

Participant 4: In most cases other people, they thought that I was completely different; they thought I was a monster because they hadn't seen something like that. It was

difficult to form friendships because of that. I remember there was one little girl, like every time I even got close to her she ran away. Even talking it wasn't one of those things that could help.

In this instance, we see how othered the participant was as a young child at school and that any remediation of this experience was exceedingly difficult as he had been rendered different to the extent that he would not be engaged with by some peers. We also see that the participant is constructed as aversive *(I remember there was one little girl every time I got close to her she ran away*). The participant is specifically constructed as a monster (*they thought I was a monster*), the kind of construction that brings to mind being turned into something that arouses fear and is aberrant in a clearly negative way – being viewed as an 'ugly terrifying being' in keeping with dictionary definitions. Thus, in many respects while they experienced themselves as treated often with contempt or hostility the participants were in a sense simultaneously constructed as dangerous or malevolent (in keeping with the snake analogy introduced earlier). This mismatch between self-experience and how they were viewed by others contributed to puzzlement and wounding *(I feel sad about that*).

The participants were stuck in being constructed as occupying bodies that children fantasied about in regard to their origin, rather than being engaged with as peers who were the 'same as':

Participant 4: They see something different and they think it is this or it is that and they are quick to talk about it, then a whole lot of stories come about and they believe that easier.

Participant 2: I remember playing alone, these two kids from Grade 3 were close to me and one guy was telling his friend like "how did he get white skin?" and he was like "he used to be black but then he cut his skin off and that is why he is white", and I didn't say anything at all.

In both quotations, there is a sense of resignation to being gossiped or spoken about, as if their albinism entailed foregoing certain kinds of interpersonal rights, reinforcing the notion that they were aware of occupying a devalued status. The idea that 'stories' get told about one reinforces that curiosity and objectification went hand in hand with being born bearing such a visibly different appearance. Erikson (1968) notes that identity formation has its roots in childhood and through the above quotations we are given insight into the participants' difficulties with the ways in which they were perceived and responded to, difficulties that appeared to have long term implications for their identities.

Amongst the participants, who were all what would be categorised as 'black' South African males in terms of their family heritage, the racialization of their condition is considered. In some instances, as in the above quotation, transformation of the body is considered to be that which causes the individual with oculocutaneous albinism to differ from his black counterparts - the participant's body in this instance is placed in an in-between space of black becoming white. The reference to the conversation overheard about how he may have become light skinned, retained by Participant 2 over many years, suggested that his condition was depicted in the children's fantasy as entailing a gruesome and unnatural process (*he cut his skin off*), conveying their

sense that the participant's being was unnatural. It is also interesting that for the boy who volunteers this story there is a lack of awareness that one might be born with this condition. There is thus some sense that the identity was self-inflicted, suggesting that as a child Participant 2 had to carry a greater sense of responsibility for his own condition. The manner in which race played out in the interviews with the participants will be considered at greater length later in the chapter. For the purposes of the present discussion, this quotation serves to show the ways in which the participants grew up having to engage with experiences of being viewed as distinctly different, and that this difference almost inevitably carried negative connotations. The communication of difference was often through being teased by children they engaged with and also by being ostracized and othered within their own racial grouping. Participant 2 reported that he felt shamed on this particular occasion, and that he had neither been able nor willing to respond to the children discussing his being largely because of his own confusion and shame (*I didn't say anything at all*). It was evident however, as with many of the other incidents recalled and recounted by participants, that this memory of being discussed in this manner by his peers had stayed with and affected him into adulthood.

A counter experience to this is a participant's experience of encountering another child with albinism for the first time.

> *Participant 4: I remember when I walked into one of the classes, I was with my parents on a tour of the school, and I saw another person with albinism and I was excited and I was like "Ma, Ma, look it's another person like me".*

In this memory we hear the participant's excitement about even seeing someone whom he felt he could resonate with, an indication of how powerful his experiences of feeling different in relation to those without oculocutaneous albinism had been and what a relief it was to encounter someone who looked 'the same' (*another person like me*). It is important to recognise that there may have been disconfirming experiences with regard to stigmatization, but it was generally the case that all of the participants, rather uncomplainingly, had received difficult and hurtful kinds of communications about their albino identities.

Participant 1 talked about people needing time to accept him: *Yeah, because they get used to what I have, I want them to get used to my condition first and then things can develop after that*. In the quotation below he talks to the safety in this regard:

> *Participant 1: I felt fine when I was around my family and very close friends… I knew they were fine with everything, they didn't feel anything untoward to me…*

There is an apparent safety net created by being known by those around the participant and a fear in being around those that the participant was not known to in case something '*untoward*' might take place.

It was evident in all of the interviews that reflecting on life experiences as a boy or man living with albinism evoked recollections of being confronted with how alien their appearance was to others in their communities. Moreover, the memories carried allusions to how abnormal they appeared to others (animalistic, thing like, monstrous, painfully mutilated by means of skin removal). Since children appeared to filter their

responses less carefully than adults did, many early experiences of stigmatization occurred in interactions with peers, outside of the home early in life. It is likely that the participants as boys had little explanatory appreciation of their own condition and were therefore more open to being interpolated in particular ways by others. They tended to receive and absorb such experiences rather than being able to reflect upon them or explain their appearance to others and thereby engage in communication. One consequence of these kinds of negative identity related communications was to develop feelings of shame. The participants all reflected on their experience of having a condition that is manifestly identifiable to others in public spaces. Their hyper-visibility was in many respects a precursor to being engaged in a way that was shame inducing and is therefore discussed prior to elaborations of the sub-theme focusing on the development of feelings of shame.

4.2 VISIBILITY IN PUBLIC SPACE

For the sake of clarity, the discussion regarding the implications of having a condition that brings with it being visibly different and noticeable in public spaces has been organised in a particular manner. It is useful to first consider some recollections of how the participants have been identified in different ways when in public. Following this discussion, the narrative moves to consideration of how these experiences appeared to play into the internal representations the participants had and still may have of themselves as ‘other’. The discussion related to hyper-visibility also clearly links to the previous theme Stigma and Being Othered as well as the theme following,

Internalization of Shame and Self-doubt and Self-protective Measures, but foregrounds the importance of exposure through carrying a highly noticeable identity.

> *Participant 3*: *…it is people that see me for the first time though, those people, yeah, they are marvelled and are surprised. You can see it with the young kids they are curious or maybe they shy away. A typical example is me shopping at a mall, some kids, irrespective of race will come and touch me, they are curious, they want to see if my skin is plastic. One kid even put his hand in his mouth and used his saliva on his finger to wipe against my skin to see if it was real.*

> *Participant 2: … even to this day we will be in the shops or whatever and standing in the cue, and people with little kids will just stare. They can't know better but it is still disconcerting. It feels like I am different from you but do you need to stare at me. They probably going to ask their mom later on "mom what was that person?"*

These quotations highlight the participants' experiences of being very overtly identified and noticed as being different and turned into oddities in the minds of the children who they are talking about. In both statements, the interviewees share general experiences that seem to be frequent occurrences. Participant 2 seems to experience this identification as being painful *(it is still disconcerting*), as he is scrutinized by children in public in a way (*people with little kids will just stare*) that would generally be considered rude. From the quotation it is not entirely clear whether it is only the small children, or whether it may be their parents too who scrutinize him in this way. His experience of others as they see him for the first time is one where they see him as different and he notices this in their reaction to him (*they are marvelled and are surprised*). He suggests that in younger children this can translate into aversion (*maybe*

they shy away) and perhaps infers that adults may feel the same way, but be better able to inhibit their responses.

We see that the participant's fantasy is that the child may not see him as being wholly human as he considers what the child may ask his mother later – "*what was that person?",* Participant 3 is treated in an even more intrusive manner with children feeling entitled to move into his private space and to physically test his 'make up'. He reveals his fantasy that the children who engage with him may think of him as not entirely human as he considers that they may seek to determine if his skin is real or not *(they want to see if my skin is plastic*). It is apparent that this is Participant 3's construction of how he may be being viewed on the basis of how he has been physically treated by children in public settings. As with the earlier discussion of being constructed as in some way being sub-human or non-human, the participants' physical appearance seems to invite a response in which their shared 'humanness' is openly interrogated, at least by children who are not inhibited in their behaviour. The impression is also conveyed that parents or adults do little to prevent children from reacting in this manner.

While the two quotations presented above talk specifically to children's engagement with the participants, other narrative accounts highlight how the participants are also at times othered in their interactions with adults:

> *Participant 4: I remember one time there was a funeral and we were all together afterwards and during and we were just chilling. I remember a few ladies walked by, older*

ladies, and they were like "you know what, you guys look beautiful" and you know for us it was like, no, like no. It was appreciated but for us it was on the odd side because you don't usually get people coming to a group of us and telling us we look nice, that was kind of odd.

Although their comments are apparently positive there is an intrusion in this instance as the women approached the young boys and identified them as different. One may presume that the women who approached the then high school boys with oculocutaneous albinism had good intentions as they sought to be complimentary (*you know what, you guys look beautiful*). However, adopting a more a psychoanalytic perspective, from the nature of the wording and interchange it might be suggested that these women were perhaps compensating for unconscious prejudice. It is noteworthy that their intervention was experienced by the participant as *"odd*" and this needs to be considered. Perhaps this instance reveals difficulties in the participant experiencing himself and his friends as physically attractive (*you don't usually get people… telling us we look nice*), an interpretation that is also important to hold in mind, especially in relation to the subsequent discussion of the possible internalization of prejudice. What is apparent, however, is that the experience felt othering to the participant and still left him with a sense of discomfort. To be noted as a group and approached for being different seemed to have left the participant with a memory of feeling scrutinized and open to commentary. It was evident that on occasion assertions of acceptance were painful or were experienced as somewhat of a shock precisely because they suggested that the opposite might have been more likely.

Participant 2: I remember the one afternoon we were just having like a braai at a friend's house and one of them just told me "at first it was difficult walking home with you because of the looks or the comments or whatever but after some time you were just one of the guys". So that was comforting to hear, but also difficult, because if I didn't have albinism then that would have never been an issue.

We notice once more how the impingement on this participant's life and being related to being visibly identifiable as someone with oculocuntaneous albinism – someone who unwittingly invites "*looks or the comments*". This has implications for his social desirability as his friend (perhaps also unwittingly) points out. There is a sense that a kind of socialization has taken place, a 'getting used to' of the body by others, before the participant can be considered "*just one of the guys*". In the recounted memory the participant's friend seems to have had his own reservations about being turned into someone socially undesirable by being associated with the participant and indicates that perhaps he had to resist certain peer pressure in remaining connected to Participant 2. The communication from his friend seems to have stayed with Participant 1 because it was almost surprising to him, came up one afternoon when they were *just having like a braai at a friend's house,* and compelled him in the moment to re-engage with his difference. There is also some sense that the statement might have been hurtful or assumed a robustness in him about his condition that was not necessarily present, but that, as with some of the other interactions previously described, he received the communication as a kind of truth to be accepted.

In some instances, their visible difference leaves the participants being or feeling vulnerable or unsafe in a more literal sense:

> *Participant 3: I got mugged in 2011, because maybe I am seen as psychically weaker because of my condition.*

> *Participant 4: You always have to keep your wits about you. You always have to be sure to be moving in an area where a lot of people are there, in a place where you are generally going to be safe… Well the places where I walk I try to avoid areas where I perceive someone might try to do something.*

The sense of vulnerability to physical harm is linked to the participants' condition as they feel it makes them more vulnerable to attack. Participant 3 introduces the notion of being considered physically weaker due to living with oculocutaneous albinism – an interesting association that may be related to the fact that the condition often entails visual disabilities, but also seems to suggest that there may be other less literal associations to carrying (genetic) weaknesses. Although not explicit in Participant 4's statement, there is an inference that it is his visible identity that singles him out more readily for potential victimization. It could be argued that due to various historical experiences of micro-aggression the participants have encountered they may have internalized persecutory feelings and have developed heightened anxiety to threats or perhaps in reality have been at greater risk for harm.

The participants were aware of the threats and risks to those living with albinism in other parts of Africa but tended to dismiss the likelihood of a similar level of risk to them

in a South Africa. The knowledge and awareness of such risks in other parts of Africa may nevertheless have served to heighten their sense of their visibility and how this might be potentially dangerous in specific contexts.

4.3 INTERNALIZATION OF SHAME AND SELF-DOUBT AND SELF-PROTECTIVE MEASURES

Growing up in with oculucutaneous albinism arguably resulted in an internalization of being different and othered and, as evidenced in some of the previous quotations cited, produced difficult affects in the participants. A common theme amongst the participants was that of experiencing shame about their condition and themselves.

In the quotations below, two participants explained that their earlier experiences remained with them as they grew older. These experiences appeared to have attuned participants to anticipating and, where possible, fending off responses that were resonant of stigma.

> *Participant 1: One thing I avoid a lot, rejection, because you know when you get rejected you ask yourself why, and the most logical reason would obviously be my condition.*

> *Participant 2: I had trained my ear, well not trained my ear but when I didn't know people, in particular, I'd be listening out to kind of hear any negative comments.*

In the first quotation the participant can only imagine any rejection that he experiences to be the result of the oculocutaneous albinism he lives with. Similarly, in the second quotation, it seems that earlier experience has left the participant with anxiety that is associated with previous negative input from the external world linked to his condition. The participants in these instances seem to be talking to an anticipatory anxiety that is informed by previous experiences of being rejected and their early experiences of stigmatization. In both of the above quotations it appears that the anxiety related to being potentially rejected is linked to their condition. There is consequently a need to ward off possible rejection that is expected from those around the participants (*One thing I avoid a lot, rejection and I'd be listening out to kind of hear any negative comments*).

There is also some suggestion that the participants themselves have internalized that there is something problematic with their identity, even if it is that their condition attracts critical attention. It is evident from their words that external experience has translated into internal feelings of self-doubt that inform their later experiences and that their albino identity becomes centrally salient in situations of interpersonal ambiguity, rejection or threat.

Shame had been experienced, to some degree, by all the participants in more or less overt ways. For example, in an instance where a participant had been asked "what had been elicited in [his] life, living with albinism?" he responded:

> *Participant 2: Uhm, I'd probably say a lot of shame. Uhm, well, just from like, just from growing up and not, you know, not understanding why I was different.*

It was striking how quickly Participant 2 was able to identify shame (*I'd probably say a lot of shame*) as a dominant feeling state associated with his condition. The work of Tompkins (1962) concerning shame as, what he terms, a *master affect*, seems relevant here. The participant immediately identifies shame as the predominant feeling associated with living with albinism. As a master affect shame also appears to shape and colour other affective states. Participant 2 reflects on being different and links this to his experience of shame, but also links this to a lack of understanding of why he was different which left him impotent to change his circumstances and further vulnerable to lack of self-worth (*and not, you know, not understanding why I was different*). He was made to feel lacking for something over which he had no control and of which he had little comprehension. During the interview process, Participant 2 links the centrality of shame in his life to his childhood experiences (*something linked to my childhood, something that I have had in the back of my mind*). The participant's experience of stigma and associated feelings of shame seem to have affected the way in which he engaged with the world around him, producing a rather suspicious and despondent propensity. He reflects on this in the quotation below:

> *Participant 2: I'd particularly be listening out to kinda hear any negative comments that would be made… for a long time that had a pretty bad effect on me, that probably going into a day or two depression and just rehashing all my childhood feelings and rehashing what was said in passing.*

This quotation provides us with a representation of how the participant expects to receive negative input from others and links this to his earlier experiences – almost

filtering present experiences through the lens of the past. One may postulate that these early experiences left some participants with a propensity towards depressive affects and rumination (*rehashing* as suggested by Participant 2) and also perhaps, as alluded to previously, with anticipatory anxiety in relation to forthcoming social interaction, particularly in novel situations.

What became apparent during the interviewing process was that the participants felt a significant sense of comfort in being with those they were/are familiar with. While this may in some ways be considered a universal experience, what it appeared to do for the participants is protect them from the experiences of rejection that they may have anticipated. In this way, spending time with people who were known to have already accepted one became a defence against anticipated rejection and potential shame.

> *Participant 1: I was fine around my family and very close friends, but when I had to socialize, especially back in high school because I was very much in myself and with my close people, and at the time because you know, guys will be guys, we have to socialize and talk to girls. I was a bit reluctant, I was one of the guys who would just relax and have my drink. Just stare out and talk just to the people around me, so like I didn't have that thing where I would actually approach people. Because I really thought, you know that person would think, "why is that person approaching me?" because of my condition.*

We notice in this quotation the participant's fear of approaching another person because of his apprehension that they would see him as undesirable and undeserving of interest because of his condition. Again, what is reflected is an internalized sense of lack of self-worth and assumption of judgment from the unknown other. It is apparent that Participant 1 had become risk averse in novel interactions because of historical

experiences of othering and denigration. This is in line with literature that suggests that previous experiences may lead to the internalization of shame, which in turn may lead to social caution by those who experiences the shame (Herek, 2014). It is also evident as will be discussed further, that it is approaching girls or prospective romantic partners that is particularly threatening or anxiety provoking in terms of potential rejection.

It should also be noted, however, this quotation introduces the more positive notion that people close to the participant, such as friends and family, created a comfort within the participant. The participants' emotional and social experience of their condition felt more manageable when surrounded by their 'close people'. This finding was in line with a study conducted by Phatolo, Bila and Ross (2015) who upon interviewing individuals living with albinism found that they struggled to engage openly with individuals with whom they were not familiar but found safety and comfort in those who they felt knew them over a period of time. In the instance just cited, we see how the participant felt more at ease around those people that he had known for a while. We can hear this reflected from other participants as well:

> *Participant 3: Mostly people they understand, it is people that see me for the first time though, those people, yeah, they are marveled and are surprised….*

This participant reveals the notion that over time people become used to him and his condition and the latter no longer attracts particular attention. One can see that there is some relief in being known by and already accommodated to by others. Returning

to a previous quotation from Participant 2 it is evident that he also subscribes to this notion of the importance of people ‘getting used to him’:

> *Participant 2: I remember the one afternoon we were just having like a braai at a friend’s house and one of them just told me “at first it was difficult walking home with you because of the looks or the comments or whatever but after some time you were just one of the guys.”*

In this quotation we are reminded of one the difficulties of living with oculocutaneous albinism, namely, as mentioned previously, that it may place strain in the process of forging relationships, both for the person with the condition and those associating with them. The process of getting to know the participant in this instance was fraught with difficulty and his childhood friend reported that, as with more general members of society, he had also found it initially challenging to be associated with him. This may perhaps compound the notion that one is marked as different and should be wary of approaching unfamiliar others and of attempting to move beyond those with whom one feels a level of safety and familiarity. However, after some time, one can become more relaxed about the reality of acceptance. In this instance, it is assumed that there is sufficient intimacy between the two parties that the history of difficulties related to their friendship can be shared. Although, this was not necessarily evident in the data, it is also possible that the need to retain close relationships with those who do accept one may create a risk of dependence or over-compliance as the participants seemed to place particular weight on the uncomplicated acceptance of those with whom they had developed familiar relationships.

The participants are visibly different due to their condition and this has clearly had a significant impact on why they were identified as individuals to be othered. In the interviewing process the participants' experience of the visibility of their condition when in public and the associated sense of shame and potential vulnerability and denigration that it brought was a topic that they all reflected on. The participants' self-image, the way they imagined others saw them and the links to how the visibility of their condition affected their experiences were prominent themes to emerge from the interviews. The experiences of being othered and the internalization of feelings of inadequacy are in line with literature which suggests that men with identities associated with subordinated and marginalized masculinities present with internalization of external denigration (see Allen & Oelson, 1999; Clark & Clark, 1939; Kaufman & Raphael, 1996; Vu, Tun, Sheehy & Nel, 2012) with consequences for self-esteem and self-confidence. One arena in which this sense of inadequacy and lack of desirability may manifest is in relation to romantic or sexual partner relationships.

4.4 RELATIONSHIPS WITH INTIMATE PARTNERS AND CONTAMINATION BY ASSOCIATION

At the time of the interview process one of the four participants was married, two were in committed romantic relationships and one was single. All the participants identified as heterosexual. Each of the participants reflected on how their condition played into intimate partner interpersonal dynamics and accordingly a theme related to this content was delineated from the interview data and is elaborated here. As with

some other themes it is noted there is a degree of overlap in the material related to each theme. In this instance the area of overlap is with the theme of “Visibility in Public”, however in this instance the key focus is on how this visibility affected interactions with potential romantic partners in particular. Participant 1 referred to an experience of being on the beach in which he reveals the difficulty he experienced (and seems to continue to experience) in engaging with potential intimate partners.

> *Participant 1: Except when like it is like a public place, and do I think that... Women are very strange. They obviously go for the six packs. They have a certain way of looking at guys. Exactly, it does happen, basically, women want a tall, dark and handsome guy. If I walk up and start talking to them I always wonder do they feel inferior, do they feel like “why is this guy talking to me?” Like, “Am I this ugly?” I always have that, and I still have that, and I’m still trying to get used to it. I can’t get into a girl’s mind and know and say “Do you think that we can’t get along because I am like this?”*

Participant 1 feels that he falls short of what would generally be accepted as desirable for women. In the above quotation it appears that he is perhaps reflecting on his own experience of feeling unable to meet what may be considered a hegemonic ideal of masculinity. His own sexual or partner desirability is called into question when thinking about engaging with the opposite sex. There is an indication that the participant’s body leaves him feeling inferior to other men and he projects this feeling in the manner in which he imagines a woman he might wish to approach might consider him. In addition to not meeting the stereotypic body ideal that many men might feel they fall short of (*They obviously go for the six packs and basically women want a tall, dark and handsome guy*) it seems that Participant 1 and perhaps other men with albinism carry

the added anxiety of being found even less attractive than might be the norm, as a consequence of their appearance. It appears that his own internalized feeling of being physically unattractive is transposed by his fantasy into the mind of the woman and elaborated upon in an imagined inner dialogue (*Why is this guy talking to me? Like, am I this ugly?).* He wonders if his approaching them may be interpreted as a poor reflection on their desirability and by implication his own. In this respect, Participant 1 conveys his own sense of carrying an inferior status as a potential partner by implying that he is only deserving of the attention of 'ugly' girls or women. There is also an inference that for a woman to be associated with him would be demeaning to her societal status, a concern that was evident amongst all of the participants and will be further elaborated below. To some extent, Participant 1 is aware of the projective nature of these feelings as he comments on being unable to know what the woman he imagines talking to may feel about him. (*I can't get into a girl's mind and know and say "Do you think that we can't get along because I am like this?).* The participant particularly highlights the anxiety provoked in him by the idea of making a romantic approach to someone. Later during the interview, he noted the profound sense of relief and comfort that came from being accepted by his current intimate partner:

> *Participant 1: If you say: "okay you can be my boyfriend" then you have accepted and acknowledged that this guy is white. I felt like let me be free because she took me with my white body. I don't have a problem and I don't think she has a problem.*

It was notable that the participant's partner had to have undergone a "getting used to" process with him and his body and accordingly it appears that he feels safe and

comfortable with her now that the risk of rejection has been overcome. He is able to feel liberated from negative scrutiny and anticipatory anxiety (*let me be free*) because his girlfriend or partner made a knowing choice to be associated with him - *she took me with my white body*. It is clear that he regards his physical body as requiring extraordinary acceptance and there is a sense in which he appears deeply grateful for her validation of him. However, one can perhaps detect a degree of a lack of confidence in his position as he still notes some uncertainty around her perception (*I don't think she has a problem*). However, it appears that her willingness to accept him and his body despite his condition instilled in their relationship a profound sense of safety for him, signalling a movement from the anxiety evoked by engaging in courtship to the sense of relief at being in an established intimate relationship.

Participants seemed to feel particularly appreciative for partner acceptance as they worried that in a sense their partners had taken a risk in becoming intimately associated with them. What emerged explicitly in interviews with two participants was the notion that they placed their respective partners in a difficult position by being physically connected to them in public. In one powerful quotation, Participant 1 reflects on his experience of being in public with his girlfriend:

> *Participant 1: Yeah, like she is very like that type of holding hands, but like for me, I think that, I don't want her to, so I haven't told her this but I don't want her to feel that she could have a stigma towards her. Like if people were like "hey you're dating an albino, why you dating him?" and I don't want her to be under attack because of my condition*. *So you know I tend to be like, I don't want to be affectionate in public, like holding hands and those types of things.*

Participant 2 reflects on a similar kind of apprehension in relation to his wife:

> *Participant 2: Because of my own feeling of, like, no one can ever love me because of my albinism but if someone did by the luck of the draw or whatever, then I didn't want anyone else to kind of go through the same things like getting weird looks, that sort of thing. So when we did start dating I was very, very sensitive or when we went out to public places we were just looking around to catch someone staring or whatever… Anything physical of any physicality (in public) I would not be a big fan of because I didn't want to draw attention to us, even not to an extent it is still kinda is an underlying thought.*

The first quotation portrays the participant's fear of almost contaminating his girlfriend with his stigma (*could have a stigma towards her*) - the stigma he has experienced throughout his life. In his reference to her potentially coming under attack he signals that there may be some risk in being associated with him, even if it is risk of denigration. The second quotation shows us the participant's desire to remain as inconspicuous as possible and in the context of this discussion it was evident that this desire was borne out of a need to protect his partner from curious or even hostile scrutiny. Apparently, both participants think that being physically associated with them through overt intimacy will mean that their partners become subject to the same kind of (negative) scrutiny that they have had to bear throughout their own lives.

There is evidence of a fear that intimate partners may be targeted in some manner by being close and intimate with men who live with oculocutaneous albinism. The participants reveal that there is a desire to protect their partners from these negative experiences, in part by inhibiting or curtailing what might be considered normal or

appropriate demonstrations of affection when in a social context. Neither man seems to have been explicit with his partner about the cause of this behaviour and the lack of physical demonstrativeness by them in public may be open to different kinds of interpretations from partners. The participants seem to believe that their bodies (as visibility of their condition) have the potential to inflict on their partners something dangerous and that their bodies could almost contaminate their partners, rendering them undesirable to others through proximity and evident commitment. As a result the participants' partners are also viewed as potentially vulnerable and vulnerable to coming "*under attack*" by those around them.

When considering this material from the interviews one might argue that there is a process at hand whereby the participants have internalized shame due to their experiences and that they in turn fear that they would shame those that they are close to (friends and intimate partners) merely by being connected to them. It is hard for them to think of themselves as carrying positive connotations as romantic or intimate partners and there is a sense in which they see their albino identity as so prominent as to override any positive attributes. Participant 2 reveals his thinking that his condition held such undesirability that he grew up assuming that love was not an option in his life (*my own feeling of like no one can ever love me because of my albinism),* and assumed that he would be permanently ineligible as a life partner. Fears for their partners' reputation and self-esteem leave them feeling strongly protective towards them as well as grateful for their love and it is possible that this introduces particular dynamics into their relationships.

In addition to fears of contaminating partners by association, there were also fears of contaminating any progeny they might produce together. Participant 2 reflected on his concern of transferring his condition onto his future offspring.

Participant 2: Yes, something linked to my childhood, something that I have had in the back of my mind, is my worry that if we ever had kids. If they ever had albinism… I really didn't want that to ever be a factor. I didn't like the thought of my kids having to go through something like that, something like I went through. It is not a big thing like, like, I wouldn't say that it is not a concern at all. It does worry me. Not to a great extent.

Researcher: Is this something that you and your wife have spoken about?

Participant 2: Yes, we did and it was sorted between us.

Researcher: So, you did talk about it and this hypothetical child with albinism would be fine with you both but you would be worried that the child may have some difficult experiences like you have had in your childhood?

Participant 2 Yes, that is it.

Participant 2 was not the only participant to have considered this dilemma. In addition, the trepidation around passing on the condition extended to concerns about potential marriage partners for those who were not yet in committed relationships.

Participant 3: I would read about what would happen if I had offspring so that if it happened I could answer questions to a prospective spouse and the likelihood of that.

Participant 3 indicates a concern about what a prospective spouse may feel in relation to having a child with him and the risk of bearing a child with his condition, and suggests that this may compound issues of undesirability in relation to romantic partner relationships and potential fatherhood. For this reason, he has researched the likelihood of this occurring.

There is an apparent fear of bearing children that could be born with oculocutaneous albinism as if the condition might be passed on genetically. Through this fear we are given a further indication of how the difficulties and pain experienced in the participants' lives and their condition have been interlinked. This does not mean that all of their painful experiences are necessarily tied to this aspect of their identity, but certainly a great deal of suffering is indicated in relation to living with albinism. Their fear of directly transferring their condition is apparent in the quotations and there was also some indication of a fear of contaminating their children with shame and stigma by being associated with them as parents. Interestingly, none of the four participants had yet produced any children. While this was probably primarily linked to their age and relationship status, it may be that the anxiety of producing a child with albinism also contributed to some inhibition in this regard. Clearly, the participants would not want a child of their own to endure similar suffering and in their communication, there is reinforcement of the previous observations that living with oculocuntaneous albinism comes with heavy affective weight.

As has been indicated before in the chapter the themes that emerged were strongly interlinked. In the quotation below, Participant 3 reflects on what he calls a superstition in his community. Here we can notice the interplay between stigma, shame, visibility and contamination of others through association:

> *Participant 3: I mean amongst blacks it is a superstitious exercise and I have seen them, because it is me, when I walk by them it signals bad luck. So, to eliminate the bad luck the person with albinism gives them they open up their shirt and spit on their chest.*

The stigma here is clear, the participant is treated as something less than and physically contaminating even to strangers – he signals bad luck. He is othered and dehumanized in the manner he is reacted to and while he recognizes the person's response is rooted in superstition he still has to tolerate the manner in which this places him on the margins and constructs him as capable of harming others purely by being in their presence. The quotation brings to mind the experience of being called a monster, discussed previously. In this instance, Participant 3 is also constructed as aberrant and reacted to in a negative fashion and it is evident that the idea of someone wanting to be intimately associated with him by touch feels unlikely. While the participant does not overtly say this, it is not a far stretch of the imagination to think about the shame that is evoked in this process. This entire 'superstitious' process takes place because of the participant's condition which is one that makes him very noticeable in a public space. The people in the street can identify him as having oculocutaneous albinism and react in a way in which they project onto his body their 'superstition'. Considering projections in a psychological way, one may argue that the participant's body becomes the object on which others project their own feelings of

“badness”; projecting aspects of disgust, dehumanization, aggression, threat, and fears of being unacceptable or marginalized. In other words, the participant becomes the bearer of the bad in his community space for individuals who react this way. Again, one can appreciate that there is fear that others close to him may be subject to the same kinds of projections by association.

The participant’s physical proximity to the community member in the above quotation brings about the perceived need for the person to literally spit out what they have ‘received’ from him. He is positioned as contagious and accordingly there is a need to expel the bad luck his closeness brings to them. This is done in a physical way by spitting – an apparently consensually understood ritualized response. What is worrying in this regard is that the participant seems to be talking about his experience in general rather than about a single incident. One may accordingly postulate that this is a relatively common experience for him in his community setting and therefore a relatively common way of positioning individuals living with albinism. Hearing about this experience was particularly difficult as there was a visceral quality to the account that brought home the intensity of stigmatization that had to be borne in certain instances by participants.

Having emphasized the dominantly negative experiences and associations participants reported as a consequence of living with oculocutaneus albinism it is important to document and elaborate some of the more positive features of their life experiences that were apparent in the interview data.

4.5 COMFORT IN MY SKIN: ACCEPTANCE AND POTENCY

A frequent experience across the interviewing process was one whereby the participants spoke about positive adjustments they had made and ways in which they became comfortable in their own bodies both through their own reflection as well as through more externally based experiences of acceptance and love. Accordingly, this theme entitled 'Comfort in my Skin: Acceptance and Potency' considers the ways in which participants' positively adjusted to their own condition, made meaning of their experiences and/or had positive experiences they could internalize.

For one participant inclusion in a traditional process of becoming a man or initiation seemed very important in his own process of experiencing inclusion and being seen in a positive light. As discussed in the literature chapter, masculinities are located within a context and culture, and the hierarchy within masculinities is contextually and culturally informed. Participant 1 talks to becoming "*Umagwale*", a male initiate into manhood in accordance with isiXhosa culture:

> *Participant 1: After you come back from the mountain you wear a blazer to school… that blazer comes with a sense of dignity. So when I had that attire on I was with my brothers from the bush, we were together. I think those kids saw me as one of those guys.*

In order to reflect on this participant's positive experience of inclusion into a certain kind of masculinity it will be useful to consider his experience of "*those kids*" which he

discussed during the interview, prior to venturing the observation contained in the quotation above. He had previously stated:

> *Participant 1: These kids (*in his community*) would ask "why are you white?" I have a little brother and they would ask him "why is your brother like that". My brother knew but he didn't want to explain, I think he felt uneasy… so I would talk to them and say this isiXhosa word "Udaliwe", this basically means you were made by God like this. Even if you have Down Syndrome, or you are retarded, they say "Usisdalu" which is the same thing, you were made by God like this.*

Considering these two quotations together there appears to be a later compensatory experience of being accepted as '*one of those guys*', in this instance 'one of the men', following a history of having to actively forge an accepted identity in his community (explaining that he had been made the way he was by God). Before exploring the positive adjustment, it is useful to look at his positioning before his traditional emancipation process. The children in his community displayed a difficulty in understanding him, there is confusion about his racial identity and the participant is placed into a position where he has to liken himself to someone with a different form of disability with physical and mental implications in order to explain his condition. This alludes to a lack of understanding or at least a lack of communication in his context about his condition. The participant speaks about even his brother holding a sense of uneasiness around his being 'different' and shying away from him.

It appears, however, that taking part in the traditional process of becoming a man afforded the participant a sense of inclusion and in a sense access to a piece of the

masculinity pie. It seems that his graduation from the initiation process offered him greater proximity to hegemonic masculinity within his context (he can wear *the blazer* that is publicly associated with successful negotiation of the initiation process). The participant talks about a sense of dignity and later in the interview thinks about this process and recounts, "*It was a mini victory for me*". He seemingly is able to win and claim a more valued sense of masculinity in his inclusion in this traditional process. Unlike during previous experiences where he has to explain himself to the children in his community he sees himself as being understood as being "*as one of those guys*", as one of the men in the community. There is a sense that as he is included in a culturally- based traditional process so too does he feel included in the community in a more integrated manner. In this instance, his masculine identity is not called into question by its intersection with his albino identity.

Another participant echoes the significance of being integrated into a group or community as he reflects on becoming a member of his church.

> *Participant 3: It was a very big turning point actually, because before I had to face everything alone and be in my own comfort zone and before I had been longing for acceptance. Just being able to accept a person the way they are was, it was something I really longed for. I obviously tried to find that by putting extra emphasis on my friendship, if I showed I cared deeply for them, and hoping to get the same sort thing back. But church was definitely a turning point because I got involved in the church family and found acceptance without condition, people seeing your potential and not putting limitations on me based on what I looked like... the stuff kind of fell away like being*

hypersensitive to listen out and it slowly fell away and I started being comfortable in my own skin… I started to just to live life like a normal person I suppose.

In the above quotation the participant also reports having been through a process of feeling accepted and made to feel welcomed and accepted as part of a broader community. He appears able to retrospectively think about this process and reflects on his own wish in individual friendships to gain this experience of acceptance and inclusion. However, there appears to be power in the community-based acceptance that he gains from the church, perhaps linked to feeling accepted by numerous people, a whole community, some of whom he would not necessarily come to know personally. This sense of reassurance in being a part of a community and its connection to a positive sense of self is in line with literature on identity formation (Taylor & Oskay, 1995; Usborne & Taylor, 2010). This issue of acceptance by a community of people is distinct from the previous theme of finding safety in familiarity, although it is linked. Perhaps the nature of a community level of acceptance also brings with it the feeling of being safe, but unlike in a dyadic friendship the community brings an experience of being embraced by a collective. In particular Participant 3's experiences this as unconditional acceptance and suggests that this acceptance to some extent rectifies his previous experience of the biases inflicted on to him due to his appearance allowing for realignment of his sense of his identity. Although churches are commonly referred to as families, it seems that Participant 3 signals something important in his use of this word, a strong sense of being made part of a loyal broader group of people with whom he belongs. Community-based acceptance may in some way represent a microcosm

of a general societal acceptance, an experience the participant clearly craved *(It was something I really longed for*).

The participant makes the link between this level of acceptance and as he puts it becoming *comfortable in my own skin*, his skin being the primary basis on which his difference is commonly identified, the phrase accordingly taking on an added significance in this context. He correlates this feeling of being accepted to his own positive adjustment into feeling more capable of experiencing the world around him and others in it as benign rather than, as has been noted earlier in the chapter, living with anticipatory anxiety of being rejected by others.

Participant 3 had also managed to find and connect with a group of men also living with albinism and this seemed to provide him with a thinking space in which he was able to process earlier experiences. Below are two quotations from his interview, one in which he reflects on his early experiences with peers and the following one in which he reflects on his experience later during the interview.

> *Participant 3: So now the one experience I remember, I think it was in Grade two, I had a few friends but a lot of the people were like "no, no, no, he is different".*

> *Participant 3: In high school, I had a lot of friends with albinism. Back then we would just chill together… well as guys we would talk about what happened back then when we were younger…We all understand and we all know that this is what happened, but to get angry about it, it never really came about because we all understood.*

It appears that this participant found a group of individuals with whom he was able to reflect on shared experiences. Although this is a tentative observation, it was my impression that this participant had a positive relationship with the world around him and seemed to have less anticipatory anxiety about rejection than the other participants experienced. While this may be rather speculative one may consider the role that his relatively early experience of meeting others with whom he could jointly reflect on his experiences, particularly as a young man living with oculocutaneous albinism, may have allowed him a more positive sense of self from which he then experienced and related to others. Supporting this contention that support in processing experiences of rejection and othering might be particularly helpful for people living with albinism is the fact that Participant 3 was the only participant who spoke of a childhood in which his parents would reflect with him on his condition and his particular needs: I actually come from a family that understands what albinism is and they understand what the needs of a person living with albinism is. These foundational experiences may have formed a way in which the participant could more readily engage with others and come to feel 'comfortable in his own skin' – although one should not lose sight of the fact that this is also the interviewee who spoke about longing for acceptance prior to becoming part of his church community. While such life influences may evidently ameliorate some of the difficulties associated with living with the condition, they may not eradicate them.

Sport was one of the methods in which two of the participants were able to gain a sense of acceptance. They found that despite the ways in which their potency was brought into question due to their condition they were able to compensate to a degree

for this.

> *Participant 2: Yeah, no well obviously yet again this is where the short sighted thing comes into play, I wear contact lenses for sports, so say for instance some of our games, some of our soccer games are played at night and I'll wear my contacts… sometimes I miss the ball, but like it's not a big deal, like I don't let it get me down. I'm just doing it for fun, more something to do with friends.*

While the participant's visual acuity hinders his capacity to perform in the instance, he notes that the sport became a means of connecting and gaining acceptance on a social basis (*I'm just doing it for fun, more something to do with friends*). Participant 1 also reflects on his capacity to play sport and the manner in which he persevered despite his disability:

> *Participant 1: I played a lot of sport growing up. The thing is I knew I couldn't play first team cricket cause my eyes weren't so good. I know I had the skill and everything, but I couldn't, that was the one thing. The biggest thing was my eyesight, but all-in-all it was fine.*

Notably the participant is able to reflect on his skill and capacity as well as the manner in which his condition hinders him in this regard. He notes that he would have been able to play in the first team, which would have come with higher prestige and certainly more claim to a hegemonic masculinity, but was unable to as his sight problem inhibited his achieving peak performance. However, Participant 1 states that sport allowed him to gain a sense of agency as he notes: Of course, my parents were like

"*no you can't do this because you will exposed to the sun*", *but I was like "no it's fine. I have to live*". The difficulty in navigating both the restrictions associated with his condition and his drive to live a more 'normal' boy's life are notable here - masculinity, sense of self and albino identity all intersect but he finds a way to negotiate largely successfully through this. In referring to his skill (I *know I had the skill and everything*) it is evident that Participant 1 is able to own some positive attributes in an unselfconscious way and it was apparent that he had enjoyed overcoming his parents' worries and proving that in the physical arena of sport he could embrace a competent masculinity.

Two participants spoke about more recent experiences whereby their condition became treated as a socially desirable commodity of some kind. In both instances, it could be argued that the participants are again othered in some way, however their experience of this is positive and they both seems to relish in their experiences.

> *Participant 4: Well, my girlfriend likes that she is dating a person with albinism. Well, she doesn't particularly like it, for her it is more like a bonus… well not a bonus like one extra kind of thing. Well, you know generally, when you touch your skin; well with our skin it goes white if you touch it. Every time she touches it she is excited and she likes that. She can't do that with anyone else. It is basically, that she is doing something different that is intriguing.*

In this instance, the participant's intimate partner finds an excitement and gratification in his skin being different due to his condition. The participant uses the word "intriguing" to describe the way in which his partner experiences him. He describes that his

condition becomes a “bonus” or gives him some kind of surplus value (*one extra kind of thing*) in regards to his relationship with her and it adds to his appeal. Participant 1 also found a ‘bonus’ in his condition as a fashion designer whose collection revolved around albinism approached him to enter a modelling competition.

> *Participant 1: This girl said to me “hi do you want to do modelling” and I didn’t understand I was thinking, why would she think, me, in particular. I was with this other guy and I was sure she was talking about him. She told about her range that was about albinism… I went and there were almost 200 models, male and females and other people that had come to watch…when I walked out there were gasps, it could have been my ears. It was like a mixture of surprise and like when I went out there were huge cheers. I mean HUGE, like, I felt like compared to the other guys, people were cheering me much louder… I thought to myself, maybe this could be great for me… There was another show and they eliminated eight and I was part of the last twelve. That experience for me was just brilliant because there were rehearsals, I spoke to people. I got to see an arty side. Before then I was strictly let’s read books and science and that type of thing…. I felt like in the experience I gained a lot of confidence. Well, I regained a lot of confidence, let me put it that way. Then of course I didn’t win or anything, the guys who won were very experienced models. In that experience, yeah, I just felt I gained a lot.*

In this lengthy quotation, we become privy to the participant’s experience of being approached to be a model. It appears that this is linked to his albinism as in his recalling of this experience he notes that the person who approached him had brought up his condition in relation to her own work in the fashion world. It is a growing phenomenon in the fashion industry that models with albinism are being valued and sought out. The

participant initially is surprised that he may be considered attractive and presumes that the individual he is approached by is talking to someone else. He reflects on how the audience in this process embraces him whereby he is met with “cheers”. He is not only accepted, but beyond this is also made to feel special and as a consequence of his appearance linked to his condition is put on a pedestal. The participant talks to being invited into a new world where he is highly valued. Interestingly, he describes a relatively reclusive lifestyle before the experience in which he sticks with his “books” and “science”. In his experience as a model he is very much socially active and is placed on a stage and admired. Clearly, this experience marked an important development in his internal world as he notes gaining more confidence from it and speaks about the experience in a way that is highly positive. One wonders about the way in which such a powerful experience contributes to shifts in the participant’s internal world in relation to his previous experience. It is this participant who was afraid to approach women for fear of being rejected and associated himself with ugliness by inference (I really thought you know that person would think, “why is that person approaching me” because of my condition). In the modelling experience it is his body and his appearance that brings with it acceptance and adulation, and one may even argue, the desire, of the crowd. It could be postulated that in this experience the participant undergoes a retrospective mastery of his own place in the world and gains an experience of a certain kind of masculinity closer to being hegemonic (and all that is associated with this, such as being sought after, being powerful, being attractive) and far removed from feeling marginalized or subordinated.

All the participants who participated in the interviews appeared to have grown to accept their condition and the consequences that were involved with living with oculocutaneous albinism. During the process it was noticed that the participants had the tendency to take on the position of ‘wise men’ who were able to make sense of the ways in which they were treated and were able to generally accept or excuse or pardon those that treated them in untoward ways. With each participant there was an acknowledgement that a need for further understanding of oculocutaneous albinism exists. Each initial interview with the researcher ended with the question “what was your experience of being interviewed about your experience of living with albinism?” In all instances, the participant responses were positive, in part because participants felt that it was important that their life experiences were made more public for psychoeducational purposes. The quotation below is used to illustrate how this could also potentially be linked to the research findings and discussion.

> *Participant 3: It was a good experience it is good to see that people that don’t live with the condition are taking interest. We can hope that good new things could come out of younger students to improve our lives with albinism, a good thing to change our lives with a fresh pair of eyes.*

The participant advances that he anticipates that the research may be useful as it may pave a way towards understanding albinism and with this could come new kinds of treatment towards those living with oculocutaneous albinism. It is submitted that his response reinforces what has been discussed in this chapter concerning the negative treatment of those living with the condition, but also suggests a sense of hope for

change. Throughout the interviewing process the participants' reflected their desire for the education of others regarding their condition.

Four different quotations from each of the participants are discussed below. The participants locate the negative treatment by others towards them as largely beyond their control and indicate that their treatment has been caused by a lack of education concerning their condition. They are able to acknowledge that it is the other who is in the wrong, framing it in these instances as being due to a lack of knowledge or understanding concerning their condition, rather than about their being aberrant or deserving of such treatment. This is a profound shift when considering their reports of earlier life experiences in which the participants' appeared to locate many of their negative experiences as situated within themselves and their bodies (as seen under the discussion of shame and associated affects).

> *Participant 2: There is a lack of understanding, for the most part I don't think that people mean to say mean and nasty things, but because there is a lack of understanding.*

Other participants reflect on their own role in educating others. In relation to a photoshoot around albinism, that participant 1 was asked to be involved in, he ventured the following:

> *Participant 1: I owe it to my people, more than to myself, not people with albinism, all people. There are misconceptions and crazy ideas. I feel like I could have the power to change a mind or two through the project and that would be great.*

Participant 3 also spoke about taking a more active role in relation to educating others in the context of describing children approaching him to touch his skin:

> *Participant 3: Recently I have become comfortable with it. It is good to present someone with an opportunity to learn.*

The participants hope and wish to engage with the world around them in different ways and to use themselves as tools to communicate and educate others about their conditions. Participant 4 reflects on how locating his experiences of being othered as a consequence of a lack of understanding keeps him safe from entertaining and expressing feelings of hate and anger. He states in this regard:

> *Participant 4: I started looking at how I can inform them rather than hate them… I have learnt to manage [*discrimination*] with people… I try to look at what they don't know and try to explain it.*

In each of the four quotations one may argue that the participants take on the position of being understanding of others, perhaps even excessively so, and excuse their mistreatment by others by attributing this to ignorance. Throughout the interviewing process there was very little reference to anger and aggression despite being so clearly prejudiced against. This absence of hatred was apparent during the interviews of all four participants and is worth noting. The participants seem to take on a more active and less passive identity position in calling for the education of others regarding their condition and viewing themselves as champions in this regard. There is some sense

of a positive reframing of identity related experiences such that if they are able to overcome their own feelings of inadequacy they are able to engage others in a more agentic way.

The themes up until this point have been written up in such a way as to reflect aspects of the participants' developmental history and in a sense the manner in which they had come to terms with the impact of the condition on their lives over time. It emerged from the interviews that the participants experienced stigmatization and had specific responses to this stigma in somewhat different ways depending on the developmental stages in which they found themselves and their personal psychological development.

4.6 RACIAL IDENTITY

A further important theme to be considered concerns the participants' racial identity and the significance of being black men living in pale or white-skinned bodies. Each of the participants brought up racialized experiences linked to their condition and their visibly white bodies. In the quotation below Participant 3 reflects on how others struggle to identify his racial grouping.

> *Participant 3: Well, sometimes amongst black people I feel I am seen as white and amongst white people, I feel I am seen as the other race. It does happen… I don't feed my mind with such thoughts. I am aware, but I don't get filled with it.*

The participant has had the experience of others regarding him as being from a different racial group of both white and black persons – consequently occupying a kind

of in-between racial identity. He reflects on not allowing himself to be affected by the confusion of others around his racial identity. However, as he brought this up in the interview it appeared that experiences of this kind have remained in his mind, despite his conscious intention not to let such classifications preoccupy him (*I don't feed my mind with such thoughts*). Interestingly the participant does not talk to a particular experience but rather to a more general sense of being categorized as either not-black or not-white enough. These kinds of experiences seemed to bring to the fore some questions for him about where he in actual fact belongs in terms of racial categorization and inform his internal experience of his racial identity.

Reinforcing the reflection that the white skin associated with albinism complicates how one is racially categorized and perceived, another participant also reported on a concrete experience of his racial identity as a black man being misjudged by someone in his church:

> *Participant 2: This one lady from church thought that my parents must be white and when my sister came down to visit she was very taken aback and thought that my sister was adopted.*

The woman in his church had clearly categorized Participant 2 as a white man and was surprised that his sister was black. Unable to disregard her previous impression easily her immediate reasoning was that his sister must be adopted, as she was black. This manner of reconciling the appearance of the two siblings could perhaps be understood to reveal a hierarchy of racial groupings in this woman's mind as the black child, as

she sees it, must be the adopted child, who the white family with more resources has taken in. However, the key issue seems to be that this fellow church member (whose race is not mentioned) cannot divorce his racial identity from his skin colour. It appears that the participant takes up the position of a white racialized identity in the other person's mind due to his physical appearance. While discussion of issues such as racialized hierarchies and what it is that determines racial categorization and how this relates to skin colour and external appearances is beyond the scope of this particular project, it is evident that their appearance caused difficulties for participants in terms of where to locate themselves in a highly racially conscious society.

In another instance a participant spoke about his experience of having to send a picture of himself to a potential partner on social media:

> *Participant 4: Like, for example, they used to asked your A/S/R/L (*age, sex, race and location*), and you know the R is for race and I would always say I am a black person. After talking for weeks or so they would be like "okay can you send a photo" and I used to think "okay fine, I will send one". Now if you have to look at the person on the other end, like imagine I told you I am black and then a picture comes through of a person with albinism and this is just not what you are expecting. Like, think about it, all this time those girls had a mental image of this person and then all of a sudden then literally the main idea of skin tone was completely off. I mean that threw you off, like you may think after all this time "eish how come I was not told about this". So that is one of the things I picked up on, so much so that I wouldn't even ask for pictures and only occasionally if the person was comfortable enough and I had a sense that the person was the kind of person that wouldn't find this odd or strange and then I would be able to send a picture. It's important*

that I can think "okay, I have built enough of a relationship with you that you will be able to see past this".

In the above quotation, the participant claims his racial identity as black but talks to the preconceptions that come with this, namely that your skin looks a certain way (dark coloured). The participant reflects on how a certain mental image is brought to mind when considering a black male and that his condition is not in line with this. Resonating with some of the previous thematic discussion, it is apparent that he thinks the potential partner's associations to his appearance will be negative. However, his emphasis here is on the degree of surprise that the other person may feel and that he may even be seen as dissembling in some way to claim a black identity. He appears to have to prepare towards sending a picture of himself to these potential partners based on his feeling of some degree of safety in the interaction and his sense of being able to manage responses that reflect what others may consider as "*odd or strange"*. Racial identity brings with it in this instance a physical image of how a person of a particular race must look.

Interestingly, other participants were able to reflect on how language and racial identity are inter-related in a way that might complexify or bring associations to skin colour into question. With reference to the children in his community, Participant 1 said the following:

Participant 1: They will ask me if I can speak English then I speak IsiXhosa to them and they are amazed… If there is a new child that comes they explain to him I am Xhosa, I can speak Xhosa but I am white.

The children are surprised that a person with the participant's skin tone is able to speak in isiXhosa, a black African vernacular. The language is linked to a particular racial identity, namely a black African identity. While the children are surprised by the participant's capacity to speak isiXhosa (apparently expecting him to speak English is accordance with his 'whiteness') it appears that speaking an African language fluently gives to the participant a means of expressing his belonging in this racial group. Language is a means by which he is able to surpass his physical appearance, which seems to the children to be out of line with their own racial identity, and consequently to claim his position as a black male amongst the children he talks to.

It appears that the participants' physical appearance comes with a complicated relationship to racial identity in which they are not able to assume the position of a black man, which is their birthright, automatically or without problems. Instead, the participants are met with confusion from others and need to navigate their own processes of claiming their racial identity. The instance in which the participant speaks an African vernacular represents one such way by which a black racial identity is claimed or reclaimed. It is interesting to imagine how different the experience of living with albinism might be for people who have been born into what would be considered to be 'white' families or racial groupings since their appearance may be less noticeable or visible to others. It is also likely that living with albinism as a person who considers themselves as black in terms of racial identity in South Africa at this point in time

historically is particularly complex, given both the history of racial categorization and associated discrimination in the country and the current contestation around race and social positioning.

4.7 A FOCUS ON MASCULINITY

While some reference to aspects of gender identity and masculinity has been made throughout the discussion thus far this final thematic sub-section focuses in on masculinity in particular. It was observed during the interviewing process that there was very little sense of masculinity being salient in childhood related accounts of what it was to live with albinism. What was noted was that as adolescence and adulthood were discussed more content around the intersection between living with albinism and masculinity became evident.

As elaborated previously along with the Blueprint for Manhood as proposed by David and Brannon (1976), which presents prescriptions for presenting as acceptably masculine, the following have been found to be common traits associated with hegemonic masculinities; self-sufficiency, physical toughness and durability, aggression, being unemotional and uncomplaining, having sexual prowess and risk-taking behaviour (Joseph & Lindegger, 2007; Mcfecane, 2008). Participants were clearly aware of such constructions and made reference to how they saw themselves with regard to some of these attributes. Below a number of novel as well as previously cited quotations are employed to explore the positioning of the participant's in relation to hegemonic masculinities:

Researcher: What has been the major shift from not being comfortable to being more comfortable in yourself as a man with albinism?

Participant 1: think maybe I end of Grade 11, Grade 12 I had to come out of my shell really, we were all gunning to be prefect and everything so in third and fourth term, Grade 11 we were junior leaders becoming, trying to become prefects.

The Blueprint for Manhood denotes that competitiveness is one of the major tennets used by men to display their masculinity. In the above quotation it is notable that the participant finds a means of foregoing his emotional difficulties of living with his condition in order to strive to claim a sense of self and a masculinity that is more powerful and closer to a hegemonic positioning. The participant notes that he had to come out of my shell really, displaying his need to relinquish his safer and more introverted nature in order to gain status in this instance in the form of being a perfect at his high school. Later in the quotation, Participant 1 reflects on what made him a good candidate for prefectship noting: *I was very involved in school, I was in the sports teams, in the choir and I acted a bit*. It is important to note that this context was urban in nature. The same participant reflected at another point in the interviewing process on his means of 'fitting in' with what was expected of him in another context.

Participant 1: I think that as long as you do everything normally. Like you would go to the fields as a man, plant mielies (corn) and herd cows and everything else, so I used to do that as well with the guys… when I got to the (rural) Transkei I went to fetch water with the tractor, I herded the cows, I played soccer with them so I basically was one of them.

Morrell's (1994) proposal that there may be differing hegemonic masculinities that are context specific in South African is supported in the content of the two quotations. The demonstration of hegemonic masculinity shifts for the participant between an urban and a rural context. The participant is however unable to achieve the apex hegemonic state as he notes that he was basically one of them, but not quite. The participant presented as complicit in what was expected of young men in order to be seen as sufficiently masculine in order to gain a recognizable and positive status. As per the literature, there are expectations that are set out for men in order for them to claim a sense of masculinity. One of these factors is sexual prowess. The quotation below concerns a participant reflecting on the process of engaging with a potential intimate partner:

> *Participant 2: The group of friends I was in had the normal city thing, like Friday night go down to a bar or wherever but at that stage the mindset was already that I would never be able to get anyone or get a girlfriend so in those days we would go together as a group and I would sit in a corner or stand in a corner and watch them work, chatting up chicks or dancing with girls. I'd just be in the corner thinking to myself that would never be my kind of thing and that just sort of carried through and even until I met my wife that I really considered the possibility that I could be in a relationship with someone.*

The participant constructs himself as someone who is unable to engage in the process of approaching an intimate partner. He is instead a bystander who watches while his friends are able to do so. While this may be an inference from the quotation, it is of interest that it seems that the participant's friends were content to leave the participant

alone in the corner. This brings to mind a marginalized sense of masculinity, as the participant's friends are complicit in the construction that the participant was unable to engage with women in the same manner that they were able to do. The above quotation is in line with Participant 1's experience as he notes that he struggled to approach intimate partners: If I walk up and start talking to them, I always wonder, do they feel inferior, do they feel like "why is this guy talking to me?" The visible nature of albinism appears to deny in these participants any claim to a robust sexual prowess or desirability for fear of being perceived as inappropriate and being rejected. In another instance Participant 3 reflects on how his condition brings with it a denigration of his masculinity as he reflects on how he sees it as making him appear physically weaker to others.

> *Participant 3: I got mugged in 2011, because maybe I am seen as physically weaker because of my condition:*
>
> *Researcher: Do you think that your condition being clearly visible targets you as a visibly weaker man?*
>
> *Participant 3: some appreciate I am more endowed than, with physical strength and with well, even anything, like I could be better at understanding and analysing data and being smarter so ya, they could recognize that.*

It is notable that Participant 3 attempts to gain a sense of mastery as he presents himself as being potentially smarter than others as a means of remediating his experiences of being perceived as physically weaker. In the quotation below, we can

read how Participant 4 also negotiates experiences of denigration and discrimination by constructing himself as the 'bigger person' and the educator in order to gain a better sense of himself.

> *Participant 4: I started looking at how I can inform them rather than hate them… I have learnt to manage [*discrimination*] with people… I try to look at what they don't know and try to explain it.*

As with Participant 3, Participant 4 also uses his sense of knowledge (inform them) as a means of protection against his experience of devaluation. This is not an uncommon strategy amongst men who may perceive themselves as physically weaker or less robust than other men – the construction of intellect as superior to physicality. While it appeared that in many instances despite trying to conform and 'behave as men behave' the participants were/are not easily able to gain hegemonic status in terms of masculinity and tended to remain in somewhat subordinated and marginalized positions there was also evidence of resistance to this. Morrell, Jewkes and Lindegger (2012) use the term *"thoughtful masculinity*" and perhaps in engaging in thoughtful ways with those around them the participants' protect against a negative positioning in relation to more hegemonic masculinities as exemplified in the references to being smarter and able to educate others. As discussed in an earlier sub-section it seemed that the four men had been able to claim normative aspects of masculinity in different ways at different points in their lives, for example through demonstrating sporting prowess, enduring traditional male circumcision, attracting female partners and establishing male friendships. It was evident that their albinism had posed a range of

difficulties for them in relation to masculine identifications but that they had to a large extent found a way of adjusting to the constraints placed upon them by virtue of their condition and were able to live productive lives.

4.8 PROCESS OBSERVATIONS

During the interviewing process, there were particular aspects of the process that were noticed and considered to be meaningful. Accordingly, this sub-section of the discussion seeks to explore particular parts of the research and interview process and to discuss potential meanings that may be ascribed to them. The following subsection has been divided into two separate sections. The first sub-section will consider the manner in which the men that were interviewed presented their life stories and the second is concerned with the nature of engagement between the participants and me as the researcher conducting the project as part of my training as a clinical psychologist, and therefore, brings in more reflexive observations.

4.8.1 PARTICIPANT'S MANNER OF ENGAGEMENT WITH THE INTERVIEW QUESTIONS

During the interview process, it was noteworthy that the manner in which the participants spoke suggested the employment of what might be considered a rather defensive style in addressing discrimination-related experiences. As indicated previously there was little mention of anger towards or judgment of others, but rather a

degree of acceptance of or resignation to such behaviour. The participants revealed a decided capacity to be able to mentalize on behalf of those they interacted with. Mentalization is a psychological term used to describe one's capacity to consider both one's own mind and the mind of another, that is to think about and attempt to understand another's motivations, feeling, states and experience (Fonagy, Gergely, Jurist & Target, 2002). The participants appeared to consistently move to consideration of the reasons why others may discriminate against them. This was done in a way that appeared to allow them to distance themselves from their own potential anger and resentment towards others. What became clear in the interviewing process is that all the participants had been through highly injurious and insulting incidents. While there were perhaps instances in which they projected their own feelings and thoughts in interactions and occasions on which they were not able to easily ward off the hurtfulness of discriminatory reactions, on the whole it was striking how they moved to the position of attempting to understand or make allowance for the stance of the other. For example, in relation to children they took account of how novel their appearance may have been to them and of the fact that this was likely to evoke curiosity. It is proposed that while perhaps this was a somewhat defensive style of engaging, this appeared to be a rather mature or healthy mechanism created to tolerate their very difficult and painful experiences of discrimination. Having become accustomed to being scrutinized and evaluated in particular ways, they had of necessity developed an apparatus for anticipating, detecting and contextualizing the likely thought processes and responses of others. In this respect they appeared to have developed an advanced capacity to also regulate the impact of negative input over time.

The second noteworthy observation relates to the manner in which the participants presented aspects of their life stories. All of the participants were able to vividly recall particularly injurious and painful memories in which they had felt shamed or stigmatized, some of these even from early childhood. The memories constituted vivid accounts of specific events that were easily recalled – including words spoken, associated affects and context related cues. The quality of such recollections was similar to what would be expected of what may be termed a ‘trauma memory’ in the sense that the memory is recalled with unusual intensity and detail. This may indicate the nature of the trauma experienced by those interviewed, and more broadly, perhaps those growing up with albinism. The carrying of the experiences of traumatizing interactions, even if these were at the level of Identity Trauma (Kira,2010) as opposed to an immediate life threat, would also account for some of the avoidance behaviours described by the participants and the hyper-vigilance in novel social situations.

Thirdly, it was noted that there was very little content in the interviews concerning the participants' parents. Only one of the four participants spoke about parents who were able to educate him around his own condition, while another spoke briefly about being let down by his parents, as they did not do so and did not contain him. Considering the opening question that was a broad question asking about the experience of living with albinism is Africa, it was interesting to note that the participants all explained their lives in a relatively chronological way. This provided a strong sense of the development of the individuals in their own life stories. For example, the participants first recounted early childhood experiences and then moved on to discuss adolescent and early adulthood-related experiences. What can be proposed regarding the lack of content in

the interviews regarding parents or caregivers is that perhaps the participants unconsciously indicate that their early environments were such that their condition was not easily thought about or engaged with in their immediate families. This would seem to suggest that there was little containment or remediation of difficult experiences for the participants in their early environments. As a consequence, the participants may have had to learn how to manage their difficult experiences rather privately and out of a place of not really knowing themselves what their condition entailed. This may have informed their tendency to be introspective and conflict avoidant and to seek to educate others about their condition in the ways in which they had had to learn about it for themselves. It was apparent that all of them had spent time researching aspects of albinism and had found this process useful. As indicated previously, the participants' difficult life experiences seemed to impart a particular kind of wisdom and sensitivity, although this had come at considerable cost. At the same time, it was evident that they were able to hold onto positive, loving and prejudice-disconfirming experiences and to treasure these.

4.8.2 ENGAGEMENT BETWEEN THE RESEARCHER AND THE PARTICIPANTS AND REFLEXIVE OBSERVATIONS

I conducted the current research as a clinical psychologist in training and it was noted that being involved in this particular form of training as well as the participant's awareness of this might have had a particular impact on the interviewing process. The nature of the research project was explained to participants and their volunteering to participate suggested some motivation to become involved, perhaps for reasons

related to seeking to be relieved of burdens associated with their condition. The interviewing process was interactional and it appeared that there was a particular dynamic at play. Upon reflecting on the transcriptions of the interviews it was noted that the participants responded well to being heard and appeared to open up in an intimate way during the interviewing process, particularly perhaps because I had a tendency to respond empathetically to what was volunteered. While many researchers may have responded in this way, this form of response was perhaps amplified as a consequence of my training as a clinical psychologist. In addition, it also appeared that the participants may have had a strong need for their own stories to be witnessed, thought about and responded to. In the dynamic between the researcher and the participants, something was revealed that suggested that the participants have had little room to previously reflect with someone else on the importance of their experiences and how they informed their identity development and subjectivity. It appeared that the participants all experienced the interviews as ‘therapeutic’ to a degree and in line with this provided rich data as they appeared to have a great deal to express and were relatively forthcoming in what they shared. Given some of the ethical implications related to the process I was very mindful to be as respectful as possible of boundaries in exploring material in the interviews.

It is also important to address some of my concerns around how the participants are represented in the current research. It became evident in the research supervision process that I held strong personal views regarding how the participants should be represented and that this resonated with the participants' strong feelings about education and the role thereof in aiding those living with their condition. Upon reflection, it appeared that I had felt entrusted with the task of conveying, in an academic manner,

something useful as it pertains to those living with albinism. In this respect I might have been somewhat preoccupied with an activist aim beyond knowledge generation. However, I believe that in representing the participants' responses sensitively and meaningfully, I have begun to contribute in some way to deepening understanding of some of the psychological sequelae of living with albinism and in potentially helping to develop greater empathy for the difficulties those living with the condition in South Africa may face. I have also been concerned not to present the men I interviewed purely as victims or as disabled individuals and where possible

have emphasized their strengths and their resilience.

CHAPTER 5

CONCLUSON, LIMITATIONS AND RECOMMENDATIONS

This final chapter seeks to briefly summarize the findings of the current research as discussed in detail in chapter 4. Furthermore, the chapter aims to describe and discuss the possible limitations of the study and concludes with recommendations in line with the findings, including consideration of the potential for further research studies arising out of the current research.

5.1 CONCLUSION

The present research aimed to explore the subjectivity of young men living with albinism in South Africa in order to contribute to a better understanding of the impact that living with albinism has on identity formation. It also aimed to explore gender identity and the ways in which the interviewees understand and position themselves in regard to hegemonic forms of masculinity.

It was concluded that masculinity and race were salient in the experiences of the participants, in part because of their location in the relatively patriarchal and race sensitive context of South Africa. The main focus that emerged from the interviewees however, was the impact that growing up with a condition that caused the participants to be stigmatized had on their identity, subjectivity and relationships with others. Upon asking a broad question pertaining to living as a man with albinism in South Africa, the participants all began to describe life stories that mapped out their individual life-

development trajectory. Apparently, all the participants had vivid recollections of experiences of being stigmatized that included allusions to their being sub-human, inferior and contaminating. Their visible difference left them with little protection from scrutiny and public commentary. The repetition of stigmatizing experiences, generally unmediated by adult caregivers, appeared to lead to internalization of shame. This internalized shame in turn appeared to have a powerful impact on the ways in which the participants developed a sense of personal and social identity and influenced the manner in which they perceived and engaged with the world around them, including significantly how they approached relationships of various kinds. It was found that within intimate relationships the internalized shame continued to haunt participants at times and they carried concerns around contaminating their intimate partners by association.

Aspects of the stigma associated with albinism intersected with the development and taking on of a masculine identity in various ways. Notably, the participants could not at all times be assured of easy acceptance by peers and had profound anxieties about their eligibility and desirability as potential life partners. They experienced gratitude to those who accepted them and could see beyond their outward appearance or who fully accepted this aspect of their identity. They appeared to accept that they were inferior or sub-dominant men who could never really aspire to representing an ideal version of manhood, although they could strive to be good role models. One of the social identity positions they seemed to adopt was that of the non-violent man who could ‘turn the other cheek’ and who might become an educator of young children in particular by embracing their curiosity non-defensively.

An important further finding concerned the ways in which the participants were able to positively shift away from early experiences of stigmatization and internalized shame and were able to develop a level of comfort in occupying their own skin. The men were, in different ways, also able to find potency in the world around them. Much of this appeared to be linked to the experience of belonging to a broader community, for example, in the areas of religion, sport, modelling and art and culture.

All the participants, being black African males, also brought up issues related to racial identity. Being physically in a white skin but being black culturally was clearly complex, particularly at the level of social identification. It appeared that the participants at times were met with confusion or disbelief regarding their racial identity and needed to work to assure others of their group belonging through, for example speaking an African language fluently or engaging with traditional cultural practices.

In reflecting upon the interview process, it seemed that the participants had found it particularly meaningful to be given a space to unpack and share their experiences. They also seemed to have used the interview process in a constructive manner and saw themselves as contributing to knowledge generation and education about living with albinism, a project all of them were committed to.

5.2 LIMITATIONS

The limitations of the study need to be considered in order to evaluate the strengths and weaknesses of the research project as well as to inform future recommendations.

The research was conducted with four black South African males of African descent and data collection took the form of semi-structured interviews. The number of participants is one of the limitations that must be considered. Four participants form a relatively small group to base research findings upon. Given the size of the population of men living with albinism, it was a challenge to find participants as discussed previously and this affected the size of the participant group that was interviewed. However, it was also found that the participants' interviews were rich with data and accordingly it is contended that the project produced meaningful and credible findings even with the small number of participants involved. As should be evident from the discussion, it was interesting to observe how much overlap there was in the recounting of life experiences across the small group of four.

Another limitation of the study to be considered is specificity of the nature of the group interviewed in respect of their level of education. Of the four participants, three were either engaged in tertiary education or had completed tertiary education. The fourth participant, while not having tertiary education, was particularly drawn to educating himself in various other ways. The literature notes that such people are more likely to be particularly self-reflective and make meaning of various life events. All the participants were living in urban settings. Considering these characteristics of the group who were interviewed it may be noted that the current research findings might be seen as being limited to or largely true of well-educated males with albinism living in an urban environment. Qualitative research, however, does not aim to produce findings that can be thought of as necessarily generalizable to bigger population groups

and population wide generalization of the findings was not the goal of the current research. The findings appear credible and compelling as they pertain to the group who was studied. However, broadening the research population may be considered in regard to recommendations for future research.

Lastly, the subjective nature of the research may be considered a limitation of the present study. The findings and discussion of the current research are generated out of a thematic analysis generated by me with the assistance of my supervisor. This is a subjective process and it is acknowledged that biases may be evident in the manner in which the data is analysed because my own identity and history will have been influential in what I found to be relevant and meaningful. Two particular measures were used in order to curb this limitation as much as possible. Firstly, Braun and Clarke's (2006) model for conducting a thematic analysis was used to conduct the analysis and attention was paid to recommendations from Guba's model of trustworthiness as outlined in Shenton (2004) to attempt to ensure that the data was analysed in a reliable and ethical manner. It will have been evident that several quotations were used to embed the conclusions drawn within the data and also that where there was weak evidence care was taken to frame findings more tentatively. Secondly, the research was conducted and written up under the supervision of a senior academic in psychology and this provided opportunities for considering, and avoiding as best as possible, potential biases within the analysis. Subjectivity is considered to be embedded in a qualitative methodology and accordingly this particular limitation of the research is offered tentatively, but it should be noted that there may be points in the

report where conclusions were arguably over-stated or inferences were drawn that reflected a degree of interpretive license and that this is acknowledged.

5.3 RECOMMENDATIONS

The following recommendations are made in light of the current research:

- It is recommended that further research be done on the same topic with a larger population group from more varying contexts. Both urban and rural men living with albinism in South Africa could be included. Potential research may also include interviews with men of different race groupings living with albinism. In addition, it is recommended that further comparative research be done that may include comparisons between the life experiences of males and females with albinism, and comparisons between different socio-economic status groups of individuals with albinism

- The current research project involved interviews with young men between the ages of 19 and 30, as per the selection criteria. One of the findings that emerged from the research was that aspects of the young men's experiences appeared to have been linked to points in their developmental history. It is recommended that further research be conducted with a similar sample group but of a different age cohort (occupying alternative developmental stages) as this may impact the participants' views and thinking around their conditions. For example, research could be conducted with adolescents living with albinism or with men with

albinism who have already had children. Another alternative would be to do a longitudinal study mapping people's experiences across developmental periods, although this would necessarily be time consuming.

- It is recommended that research be done with parents living with children with albinism in order to get more understanding around their experiences and how they attempt to manage the challenges their children may face. It is possible that the reason parental involvement in these men's childhood negotiation of albinism was so lacking because parents themselves struggled with having produced a child with this condition and also feared some form of stigmatization and judgment. Such hypotheses would be useful to investigate further.

- It is recommended that research be conducted into potential education and awareness programmes, and the lack thereof, around albinism, in order to contribute to the development of greater understanding of the condition and hopefully reduced stigmatization. This suggests both an area for further research and an area of more applied involvement.

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APPENDIX A

Semi-structured Interview

The following broad, open-ended question will be used to start the interview once introductions and informed consent have been covered.

- Tell me what it is like to live as a young man with albinism in South Africa – I am interested in hearing about your thoughts and experiences

The interviewer will focus less on specific questions but will rather be concerned with specific areas that play into the construction of one's masculinity. As content arises that links to these areas probes and questions will be utilised in order to invite participants to further expand and explore what is being spoken about. All of these areas will be considered in relation to the condition the participants are living with, albinism. The areas that will be explored should they not come up spontaneously in the course of the discussion are as follow:

- The relationship with the body
- The functioning of the body
- Activities that involve the body, such as sport or manual labour
- Relationships with other men and women
- Sexual identity; romantic/sexual partners
- Social status and achievement

- The risk of harm and stigma around living with albinism

Examples of questions may be as follows:

- What are your feelings around being visibly different as someone living with albinism?
- In what ways has your condition affected the way you live your life?
- How do others respond to your condition, if at all?
- Tell me about your previous or current intimate relationships, if any. In what way has your condition of albinism played into these relationships, if at all?
- How were you treated at school/ how was school for you?
- Are there certain sports or activities you would like to engage in but cannot?
- If you do engage in these activities, what precautions need to be taken to protect your skin?
- Do you know of any myths or legends around albinism in Africa? If so how often are you spoken to/speak about these myths and legends?
- How do you make sense of these myths and legends?
- Do you feel safe walking down the street?
- Have you ever been called derogatory terms related to albinism?
- Do you feel as though your condition may negatively affect your safety?

APPENDIX B

Participant Information Sheet



UNIVERSITY
OF THE
WITWATERSRAND,
JOHANNESBURG

School of Human and Community Development

Private Bag 3, Wits 2050, Johannesburg, South Africa

Tel: (011) 717-4500 Fax: (011) 717-4559

Email: 018lucy@muse.wits.ac.za

Dear Potential Participant

My name is James van der Walt. I am studying a Masters degree in Clinical Psychology at the University of the Witwatersrand. I am conducting research as part of my degree and am inviting you to take part in this study. I am doing research on the Construction of Masculinity of Young Men with Albinism. Research is something that is done to find out more about a question. In this study I want to find out what your experience of being a young man living with albinism in South Africa is.

I am inviting you to take part in this research study. The interview will take between 45 minutes and 1 hour 30minutes. You may choose not to answer any questions that you do not want to, there are no right or wrong answers and you may stop the interview at

any time with no negative consequences. Participation is voluntary and you will not get any benefits or money for participating in the study.

Efforts will be made to keep your personal information confidential. Personal information will not be included in any part of the research, except possibly on the interview tape; however, personal information may be disclosed if required by law. It is necessary for me to record the interview in order for me to remember as much detail as possible. Your interview will not be heard by anyone else other than me, the researcher. I will write up your interview (transcript), all your identifying information will be removed, and use it with all the other interviews to help me write my report. The digital interviews and transcripts will be kept in a password-protected file on a computer, which only I will have access to. The printed out transcripts will only be seen by my research supervisor and me and will be kept safely in a locked cupboard. My supervisor will not know any of your personal information and will only be reading the interviews to help me write my report. It is possible that direct quotes from your interview will be used in the report, however, no identifying information will be included and they will be used with quotes from other interviews. After the report is finished, your interview recording and transcript (both digital and printed out) will be kept in their secure places for 2 years, if the research is published in a journal, or for 6 years, if it is not published, before it is destroyed. The finished report will be seen by the people who mark my report and a copy will be kept in the library at the University of the Witwatersrand. Feedback can also be given to you in the form of a letter and if you would like more feedback, I will give it to you with pleasure. My contact details and those of my supervisors are attached to this form.

If you do choose to participate, please, can you fill out the two consent forms attached and give them back to me; the one is consenting to participate and the other is consenting to the audio recording.

Please feel free to contact either me or my supervisor if you would like any further information, have any further questions, or would like to report any negative affects the study has had on you.

If you would like to report any problems or complaints that you have with regard to any part of the research process, you can contact the University of the Witwatersrand's Human Research Ethics Committee (non-medical) Lucille Mooragen**,** on 011 717 1408 or at Lucille.Mooragen@wits.ac.za

Counselling Services

We do not expect that the interview will harm you in any way but if you feel that you are having difficulties after having participated you may access one of the following free therapy services.

Emthomjeni Community Psychology Clinic	011 717 4513
Counselling and Careers Development Unit (CCDU)	011 717 91 40/32

In particular, Michelle Scott, a psychologist working at CCDU, has agreed to be a referral person.

Kind regards,

James van der Walt

(Clinical Psychology Student)

Email: Jamesvanderwalt.psychology@gmail.com

Phone: 062 027 9603

Prof Gillian Eagle

(Research Supervisor)

Email:Gillian.eagle@wits.ac.za

Phone:011 717 4528

APPENDIX C Consent Form (Interview)

I _____ consent to being interviewed by James van der Walt for his study on the Construction of Masculinity by Young Men Living with Albinism. I understand that:

- Participation in this interview is voluntary.
- I have the choice to not answer any questions I do not want to answer.
- I may stop the interview at any time.
- Direct quotes will be used in the report, however, no personal information that may identify me will be included in the research report, and my responses will remain confidential.
- There are no direct benefits for me in participating in this study.
- There are no anticipated risks for me participating in this study.
- If I feel that I am having difficulties after having participated I may access one of the following free therapy services; Emthomjeni Community Psychology Clinic (011 717 4513) or Counselling and Careers Development Unit (011 717 91 40/32) with the referral person being Michelle Scott.

Signed _____

Date _____

APPENDIX D Consent Form (Audio Recording)

I _____ consent to my interview with student and (translator) for student's study on the Construction of Masculinity of Young Men with Albinism to be tape-recorded. I understand that:

- The tape will be heard by the researcher.
- When the tape is used to write up the transcript, only the researcher will listen to it. Everything will be kept in a secure place, which only he will be able to access, while the study is ongoing.
- No personal information, such as names or places (where you live, where you are from etc.), will be used in the transcripts.
- Only the researcher and his supervisor will have access to my transcript, however, the supervisor will not know any of my identifying information.
- After the report is finished, my interview recording and transcript will be kept in a safe place, that only the researcher will have access to for 6 years.

Signed _____

Date _____