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Beyond Our Complexion: Albinism in Visual culture

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Declaration

I declare that this research is my own, unaided work. It is submitted in partial fulfilment for the degree of Masters in Film and Television at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any other degree, part of degree or examination at this or any other university. My HR non-medical ethics clearance certificate number is H15/09/19.

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1. INTRODUCTION

The aim of my research paper is to investigate the portrayal of albinos and albinism through visual culture in the South African context. The research examines the different forms of representation associated with this frequently marginalised group of people. It will also explore the relationship between these representations and real-lived concerns regarding albinism, conveyed through visual mediums of photography and film. ‘Difference and otherness’, ‘stereotyping’ ‘abject’, ‘freakery’ and ‘fetishism’ are the specific theories of representation that contribute centrally to the theorizing of this research. They are concepts that are frequently used to define and describe people living with albinism. In the pursuit to further understand albinism, a creative short film titled *Beyond Our Complexion* is a part of the complimentary research component.

The research and most of my fieldwork was inspired by two female informants who serve as the inspiration for the characters in the creative short film. Puleng Molebatsi and Regina Mary Ndlovu are both living with albinism. They are pivotal to the research in presenting their real-lived experiences of attempting to break barriers around the topic and directly addressing albinism through visual culture. The paper draws directly from Puleng and Regina Mary’s subjectivity of their personal experiences. They function as ideal subjects for the research, since both are empowered women who can speak about their experiences in direct and immediate ways; they have also been able to overcome the prejudices that they have faced socially and culturally. To clarify, this research is not intended to be a focus study research project but instead draws from the reflections of the lived experiences of these subjects. The supporting film also encapsulates many of their stories, and provides revelations on how people with albinism wish to be treated. Furthermore, I chose to incorporate audio interviews, film, photography and a stage play from those directly affected individuals to encapsulate the aims of the research.

2. Key Informants and Characters

It is vital to observe that this research could not have been thoroughly executed without exploring backgrounds and experiences of people living with Albinism; their reactions to how they are perceived and represented, and their opinions about how they wish to be

presented. I began the process by interviewing those who were already visible in the media, as they struck me as ideal candidates. Initially as an individual who was not exposed to persons living with albinism, it became evident that I as a journalist, was to embark on an emotional journey, and one that I was not necessarily equipped for. As part of my preparations for the fieldwork, I went through several articles on internet sites and looked up a few documentaries on YouTube about the topic. In order to get an up-close and personal experience with someone living with Albinism, I had a comprehensive conversation with Sibonakaliso Thubelihle Mpisi, a highly opinionated and open-minded attorney, living with the condition. This engagement aimed to establish issues around sensitivity, how to approach the substance of the topic with candidates through questioning, in order to obtain the responses that would significantly add value to my research and creative quest in making a film. I asked him personal questions that I had envisioned would be raised in the research process, and after a phenomenal meeting with Mr Mpisi, the need to pursue "*Beyond Our Complexion*" became evident.

Although Regina Mary and Puleng have different experiences and testimonies, they both attest to similar social treatment, since they are living with Albinism. The findings of this research will come extensively from their personal experiences, which was mainly obtained through in depth engagement and interviews. This proved a preferred method for both the subjects (who then became the characters in the film) and me. My journey with these two women addressed very sensitive issues and the outcome of our interactions would serve to further inform how to bring their narrative into a fictional filmic representation. As individuals, they advocate for equal rights and have a similar approach to ensuring that their fellow, very often ostracised associates with Albinism are treated with respect for their human rights. In the field of visual culture, their aim is to ensure that people with Albinism, regardless of their background, appearance and sometimes shortcomings due to their condition are given a chance of exploring their abilities without prejudice. Stemming from the audio interviews, Regina Mary and Puleng suggest that South African media, television and the arts are gradually accommodating people with Albinism. There is still however a great deal of transformation necessary to represent this group of ostracized and marginalised individuals. Although Regina Mary and Puleng are striving to break barriers, their presence and influence of people with Albinism still reinforces prejudices and mistrust.

Puleng Molebatsi is currently a television presenter who has begun challenging perceptions of people with Albinism. Her show *Bophelong* on SABC NEWS Channel 404, which

addresses the challenges faced by people with disabilities, exposes the realities of being differently abled, but also transforms what society may see as a plight or obstacle into victory. It enables people with what appears to be misfortune to be elevated and triumphant through their often unnoticeable abilities. *Bophelong* is about people who have overcome extreme challenges in their lives and they are heroes in their own right. The show's main purpose is to promote social cohesion and to give all marginalised groups an opportunity to tell their own stories. Simply securing the opportunity of presenting a show of this nature was a daunting task for Puleng, one that required her to prove her abilities, and for the technical aspects of television to accommodate her talent, regardless of her challenges on account of her appearance and her visual impairments.

Regina Mary Ndlovu is pursuing an acting career. She has appeared as a lead character in several television dramas such as *Impi ka Thandazile* which screened on Mzansi TV. The drama explores the life of a young woman with Albinism, played by Regina Mary, who faces challenges ranging from being abandoned at birth to being rejected by her community. It is pertinent to bear in mind that some of the scenes in the play *Impi ka Thandazile* stem from her personal story. The knowledge of this is key to understanding Regina Mary's cause of expressing her journey and opinion pertaining to the research in this paper and how it informs the film content.

As part of their agenda to continue advocating and raising awareness about how people with Albinism should be portrayed both Regina Mary and Puleng have acted in a theatre production "*Mama I want the Black That You Are*". The production focuses on the lives of people dealing with the prejudice affecting those with Albinism. The script is based on interviews with real people with Albinism. In the production, Puleng plays the central character of 15 year old teenager, Matlakala, living with Albinism. Regina Mary and Ntsoaki Mthiba (also living with Albinism), appear in the stage play as Matlakala's alter egos, good and bad. The alter egos serve as Matlakala's conscience, and have contrasting conversations mainly about her self-esteem. They represent the conflict in Matlakala's head, highlighting what people with Albinism are constantly faced with, due personal conflict imposed upon them by society and the manner in which it treats people with the condition.

3. Theoretical Expressions for the Research Report

In order to fully understand the framework of this research, I have used theories of representation as my focus points of reference. This paper attempts to critically examine the way in which Albinism is portrayed, by interrogating the various representations of albinism and their relationship to actual case studies. The research explores the relationship between these representations and real lived concerns regarding albinism, conveyed through visual platforms of photography and film. 'Difference and otherness', 'stereotyping' 'abject', 'freakery' and 'fetishism' are the specific theories of representation that centrally contribute to the theorizing of this research. They are concepts that are commonly used to define and describe people living with albinism.

3.1 Difference and Otherness

Stuart Hall (1997:226) suggests that representation is a multifaceted business, particularly when dealing with *difference*. He further argues that representation engages feelings, attitudes and emotions. In Hall's view, representation also activates fears and anxieties in the viewer, at immensely deep levels that are beyond our comprehension. When referring to difference, Hall (1997:238) asserts that it can be both positive and negative. He further states that difference is both necessary for the production of meaning, the formation of language and culture, for social identities and a subjective sense of the self. At the same time it is threatening, a site of danger, of negative feelings, of splitting, hostility and aggression towards the 'Other'.

Hall (1997:229) suggests that people who are in any way significantly different from the majority- 'them' rather than 'us'-are frequently exposed to a binary form of representation. They seem to be represented through sharply opposed, polarized, binary extremes such as good or bad, civilized or primitive, ugly or excessively attractive, repelling because different, compelling because strange and exotic. Furthermore, they are often required to be both things at the same time. Hall then asks about the significance of difference and why it matters? What are its positive aspects and the negative ones? Hall suggests that *difference* is both necessary and dangerous. The main argument advanced here is that *difference* matters because it is essential to meaning; without it, *meaning* could not exist. Meaning he argues is relational. The argument here is that we need *difference* because we can only construct meaning through a dialogue with the 'Other'. Meaning arises through the *difference* between

the participants in any dialogue. *The 'Other'* in short is essential to meaning. The 'Other' in short is essential to meaning. The negative side is, of course, that therefore meaning cannot be fixed and that one group can never be completely in charge of meaning.

Stuart Hall (1997:238) manages to summarise difference succinctly. He suggests there are two general points to note. He writes that from many different directions, and within many different disciplines, this question of 'difference' and 'otherness' has come to play an increasingly significant role. Then, 'difference' is ambivalent. It can be both positive and negative. It is both necessary for the production of meaning, the formation of language and culture, for social identities and a subjective sense of the self as a sexed subject. It is also associated with negativity which involves aggression and resentment towards the 'other'.

3.2 Stereotyping

According to Stuart Hall (1997:257) representational practices are called 'stereotyping'. He says stereotyping reduces people to a few, simple, essential characteristics, which are represented as fixed by nature. He examines the four further aspects of stereotyping which are the construction of otherness and exclusion, stereotyping and power, the role of fantasy and fetishism. Stereotyping as a signifying practice is central to the representation of racial difference. But what is a stereotype and how does it actually work? In his essay on 'Stereotyping' Richard Dyer (1977:1) makes an important distinction between typing and stereotyping. He argues that without the use of *types*, it would be difficult, if not impossible, to make sense of the world. Dyer says we understand the world by referring individual objects, people or events in our heads to the general classificatory schemes into which, according to our culture, they fit.

It becomes important to differentiate between a *type* and a *stereotype*? According to Hall, "Stereotypes get hold of the few simple, vivid, memorable, easily grasped and widely recognised characteristics about a person, reduce everything about the person to those traits, exaggerate and simplify them, and fix them without change or development to eternity." So *stereotyping reduces, essentialises, naturalises and fixes 'difference'*. Then it *deploys a strategy of 'splitting'*. Hall (1997:258) writes that it divides the normal and the acceptable from the abnormal and the unacceptable. It then *excludes* or *expels* everything which does not fit, which is different. Therefore another feature of stereotyping is its practice of closure and

exclusion. It symbolically defines boundaries, and excludes everything which does not belong.

3.3 Abjection

Julia Kristeva's notion of the abject as outlined in *Powers of Horror* (1982) is that what is noticeable about the abject is its ambiguous nature. It repels, but simultaneously attracts. Kristeva (1982:9-10) provides a useful approach to this matter. She is of the opinion that "We may call it a border, abjection is above all ambiguity. Because while releasing a hold, it does not radically cut off the subject from what threatens it. On the contrary, abjection acknowledges it to be in perpetual danger. Abjection itself is a composite of judgement and affect, of condemnation and yearning, of signs and drives." (Kristeva, 1982:9-10)

When analysing *District 9* (2009), Adel Nel says that besides the tension and action of science fiction cinema the spectator is constantly confronted with the dynamic of the abject which manifests in different objects, people or beings, spaces images and events that may be labelled repulsive or provocative, because they compel the spectator to look upon that which is uncomfortable, abominable, repulsive, disgusting and even perverse. Imogen Tyler (2009: 82) claims that the development of the abject falls into two categories: theoretical and philosophical exegesis of Julia Kristeva's theory of abjection, and a body of literature that applies her theory of abjection to specific areas of cultural production. The concept of the abject thus offers a useful approach to the analysis of popular culture, art and cinema.

In concurrence with Kristeva, Michael Herbst (1999:16) distinguishes between a process of abjecting (an operation to abject) and the state of *being* abject (condition to be abject). The first aspect is an active one in which one party rejects, banishes, and degrades or, in some other way denigrates another party. The state of being abject is what follows an act of abjection: it is a disposition, a place of exclusion. Herbst emphasises the relation between abjection and a politics as well as a power play, because without exception the party that does the abjecting is the one in a position of power, while the one degraded is robbed of power and the right to societal inclusion. Kristeva (1982: 4) alleges in *Powers of Horror* that abjection is seen as a symbol for 'the breaking down of a world'. Linking to this, Judith Butler (1993: 243) explains the literal meaning of the word. Butler posits that abjection (in Latin, *abjicere*) literally means to cast off, away, or out and, hence, presupposes and produces a domain of agency from which it is differentiated. The term, according to Butler thus refers to all people

who are shifted out of the centre, in other words, a specific sort of boundary crossing from one space or world to another.

For Kristeva (1982: 3), the abject is the zone between being and non-being, the border of a person's condition as a living being. She emphasizes the following characteristics of abjection. She says it is thus not lack of cleanliness or health that causes abjection but what disturbs identity, system and order. Kristeva (1982: 4) writes that abjection can explain the structural and political acts of inclusion/exclusion which form the basis of the social existence of people and groups. She points to the fact that abjection has a double manifestation. It operates on an individual as well as a collective level, and the act of abjection can thus be executed by both the individuals and the group rituals of exclusion. Herbst (1999:115-116) rightly argues that abjection is based on exclusion. What is excluded is abject. This means that prohibited things, abject things, have a certain revolutionary power, whether real or imagined, and as such they challenge the ordering formation.

3.4 Freakery

Rosemary Garland Thomson (1996:1) suggests that the extraordinary body is fundamental to the narratives by which we make sense of ourselves and our world. She says by its very presence, the exceptional body seems to compel explanation, inspire representation, and incite regulation. The unexpected body fires rich, if anxious, narratives and practices that probe the contours and boundaries of what we take to be human. Thomson (1996:3) continues to acknowledge the historical change in the ways the anomalous body is framed within the cultural imagination. She says the freak discourse's genealogy can be characterised simply as a movement from a narrative of the marvellous to a narrative of the deviant. Thomson further points out that as modernity develops in Western culture, freak discourse logs the change. The prodigious monster transforms into the pathological terata. What was once sought after as revelation becomes pursued as entertainment and what aroused awe now inspires horror. What was taken as a portent shifts to a site of progress. Thomson (1996:3) then says wonder becomes error. As portents, monsters were the premier manifestation of a varied group of astonishing natural phenomena known as prodigies, marvels, or wonders. Under the sign of the miraculous, comets, earthquakes, six-legged calves, cyclopic pigs, and human monsters confirmed, repudiated, or revised what humanity imagined as the order of things. By challenging the boundaries of the human and coherence of what seemed to be the natural

world, monstrous bodies appeared as sublime, merging the terrible with the wonderful, equalizing repulsion with attraction (1996:3).

Thomson (1996:5) suggests that exaggerated sensationalized discourse that is the freak show's essence ranged over the seemingly singular bodies that we would now call physically disabled or exotic ethnics, framing them and heightening their differences from viewers, who were rendered comfortably common and safely standard by the exchange. Thomson further points out that 'freak discourse' structured a cultural ritual that seized upon any deviation from the typical, embellishing and intensifying it to produce a human spectacle whose very somatic feature was laden with significance before the gaping spectator.

Thomson (1996:10) observes that it has come to the fore that 'enfreakment' emerges from cultural rituals that stylize, silence, differentiate and distance the persons whose bodies the freak-hunters or showmen colonize and commercialise. Paradoxically however, at the same time that 'enfreakment' elaborately foregrounds specific bodily eccentricities, it also collapses all those differences into a *freakery*, a single amorphous category of corporeal otherness. Thomson (1996:17) concludes with the notion that what lingers as a residue of these explorations is the poignant image of the freak, the person cordoned off from the rest of humanity by this embroidering, sensationalizing discourse that makes of his or her body only not a cultural spectacle but a token of the anxieties and aspirations of a society intent upon publicising the freak's private body with its stares.

In addition Elizabeth Grosz (1996:57) says the 'freak' is an object of simultaneous horror and fascination because, in addition to whatever infirmities or abilities he or she exhibits, the freak is an ambiguous being whose existence imperils categories and oppositions dominant in social life. Freaks are those human beings who exist outside and in defiance of the structure of binary oppositions that govern our basic concepts and modes of self-definition. Grosz stipulates that they occupy the impossible middle ground between the oppositions dividing the human from the animal, one being from another, nature from culture, one sex from the other, adults and children, humans and gods, and the living and the dead. Freaks cross the borders that divide the subject from all ambiguity, interconnections and reciprocal classifications, outside of or beyond the human. Therefore, according to Grosz they imperil the very definitions we rely on to classify humans, identities, and sexes- our most fundamental categories of self-definition and boundaries dividing self from otherness.

Furthermore, Grosz (1996:64) referring to Siamese twins and hermaphrodites specifically, although this is relevant also for freaks in general, says freakery is to visualise individuals who properly belong neither to one sex nor to the other is to imagine freaks, misfits, curiosities rejected by society and condemned to a solitary existence of neglect and frustrations. Few of these unfortunate people meet with tolerance and understanding from their fellows, and fewer still find even a limited acceptance in a small section of society. She writes that "they are all constantly confronted with reminders of their unhappy situation." (1996:64)

Grosz (1996:65) profoundly touches on identity and self. She says the freak illustrates our so-called normal pleasure and fascination with our mirror images, a fascination with our own identities as they are witnessed from the outside. Grosz then continues to say that this is a narcissistic delight at the shape of our own externality, which is always inaccessible to us by direct means and is achievable only if we can occupy the perspective others have on us. The relation we bear to images of ourselves is drawn from this simultaneous and ambivalent reaction. The mirror image threatens to draw us into its spell of spectral doubling, annihilating the self that wants to see itself reflected. At the same time, it gains pleasure from the access it gives to the subject's exteriority, from an illusory mastery over its image. Fascination with the monstrous is testimony to our tenuous hold on the image of perfection. The freak confirms the viewer as bounded, belonging to a 'proper' social category. Grosz further states that the viewer's horror lies in the recognition that this monstrous being is at the heart of his or her own identity, for it is all that must be ejected or abjected from self-image to make the bounded, category-obeying self-possible. In other words, what is at stake in the subject's dual reaction to the freakish or bizarre individual is its own narcissism, the pleasures and boundaries of its own identity, and the integrity of its received images of self.

3.5 Fetishism

Stuart Hall notes that, the substitution of a part for the whole, of a thing-an object, an organ, a portion of the body for a subject, is the effect of a very important representational practice. This is fetishism. Hall (1997:268) describes Saartje Baartman as an object of fetishism. When discussing Saartje Baartman, Hall observes that she did not exist as a 'person'. She had been disassembled into her relevant parts. She was 'fetishized' and turned into an object. Fetishism, provides us with what Kobena Mercer (1994a:187) calls an 'alibi'. It allows a double focus to be maintained, one of looking and not looking, thus an ambivalent desire to

be satisfied. What is declared to be different, hideous, 'primitive', deformed is at the same time being obsessively enjoyed and lingered over because it is strange, 'different', exotic.

4. Physical Challenges faced by People with Albinism

In the audio interviews, I observed that Regina Mary had challenges with her eyesight. This became evident gradually as she pretended to read the expectations and outline of the questions I would ask in the interviews. It was only after I candidly asked how she managed to browse through everything so quickly that she shyly responded that she not only had a visual impairment, but that this was also as a result of her literacy challenges. This is a common characteristic for people living with Albinism, but it does not necessarily affect all of them.

Short sightedness does however not define who they are, as according to Regina Mary, anyone could genetically or over time have this condition. She is certainly not bothered by her short sightedness as she boldly says; although she can't see far and is short sighted, she can see enough to make good choices for herself. "So I don't consider that as too much of what you define albinism to be cause different colour people have different problems." (Regina Mary:2016). In light of the above Puleng's eyesight disturbed her as a child at play with other children from a young age, and this marked her difference from others. Many would be impatient with her, often disregarding her presence when playing *hide and seek*. "The other children wouldn't hide because they knew I won't see them anyway. I would just walk pass them. So that's when I felt like I was different from other children because they could see stuff and I couldn't even see". This behaviour of the children at play and treating her impatiently, according to Stuart Hall (1997:229) is called the marking of "difference" and "othering". Hall suggests that 'difference' is ambivalent. "It can be both positive and negative and is necessary for social identities. At the same time it is a threatening of negative feelings, of splitting, hostility and aggression towards the 'Other'." (1997:238) In Puleng's scenario, being ignored and teased by her contemporaries at play was a site of hostility, perhaps an unintentional one, but one that could adversely affect her self-esteem. This teasing did not however deter her from playing. What used to be an obstacle has been overcome as she is fully able to read the autocue when presenting the show *Bophelong*. People with Albinism view themselves as normal and very significant to society. They are actually burdened by

ideas that they are associated with disability whereas for them, they are equally capable of doing what people termed normal can do.

5. Skin Challenges faced by People with Albinism

I recognised Regina Mary's change of skin tone on several occasions while filming the re-enactments for the film *Beyond Our Complexion*. On very hot days, she would change to a dark pink tone, and would seek relief in the shade. I wasn't aware of the degree to which direct sunlight affects people with Albinism, until I had several direct encounters.

Their skin is extremely sensitive to the sun and if scorched, it turns red causing physical pain. They are allergic to the sun and Regina Mary explains her misery with the sensitivity of her skin. In an agonising tone, Regina Mary explains that the sun is her worst nightmare. She says "When you burn it's like real fire on your skin and you literally feel the burning of the sun like heat. And while dealing with that, then your skin burns off, so you become red and the pain continues. I can't even touch myself. You can't even wear clothes because if anything touches your skin, it's like they are tearing you apart." It's a painful process, and often one that she has no control over. It sometimes takes days for the skin to recover, but thereafter, dries up and then the dead skin starts peeling off, creating room for fresh skin to grow.

The skin challenges of people with Albinism can easily expose them to being ridiculed by peers and society, resulting in self-doubt, self-criticism and self-pity. This exposure to being ridiculed and mocked on account of your appearance, in this case the challenges of your skin, according to Elizabeth Grosz, is called Freakery. Grosz's sentiments are that few of these unfortunate people meet with tolerance and understanding from their fellows, and fewer still, find even a limited acceptance in a small section of society. She says that they are all constantly confronted with reminders of their unhappy situation. Grosz (1996:64). Being turned into a freak and outcast for having a different appearance can create low self-esteem, so people with Albinism must find ways to address the skin problem, without allowing it to overwhelm them. Regina Mary's eyesight challenges are more manageable than the skin deficiencies. Sunscreen must always be applied on the skin to avoid burning. Background and upbringing sometimes delay opportunities to obtain information. Therefore, people with albinism are only exposed to the knowledge and the need to use sunscreen later on in their

lives. Puleng says she was from a typically low-class township family. "We didn't know about sunscreen, didn't even know it exists. So we didn't know that I needed sunscreen or what sunscreen was. So I would play around with other children get sunburnt for days." So when her skin tone started changing, her mother would beckon her to stay away from the sun. Only when she was older did she begin applying precautionary measures by wearing long sleeved clothes and a hat, but still insisted on playing outside but under shade. For both Puleng and Regina-Mary, the only aspect that differentiates them, or rather distinguishes them from others, is the colour of their skin due lack of pigmentation known as melanin deficiency.

6. Rejection faced by People with Albinism

It is often said that it takes a village to raise a child. This is an ideal embodiment in the South African context, until one looks at some of the social and cultural treatment towards people who are differently abled, or have a different appearance to what is labelled 'the norm'. I was constantly alarmed throughout the process of researching and making the film, at the myths and stereotypes associated with people with Albinism. Not only did these revelations stem from strangers, but even from people closely associated with them.

People with Albinism are often negatively labelled and treated with hostility. They are associated with cultural beliefs and myths which undermine their human dignity and existence. Some of the stereotypes associated with albinos are due to cultural perceptions that stigmatise them. The stereotypes range from mocking the physical appearances of the marginalised group, to superstitious associations which exclude them from belonging to a group or society more broadly. This 'outcasting' treatment is explained by Julia Kristeva and Judith Butler as abjection. Butler (1993:243) explains the literal meaning of the word as to cast off, away and, hence presupposes and produces a domain from which it is differentiated. The term, according to Butler refers to all people who are shifted out of the centre. In other words she says that abjecting creates a specific sort of boundary crossing from one space or world to another. Kristeva explains in *Powers of Horror* that abjection is seen as a symbol for 'the breaking down of a world' (1982:4). In relation to the above, it is pertinent to bear in mind that people with albinism have a hereditary or genetic condition, not a disease. Tragically, it still appears that transformation in especially the Black South African culture

and community will be slow in changing attitudes towards Albinism. Raimi Gabadamosi (*Mail & Guardian*: 6 September 2013), an artist and also someone living with Albinism, writes that cultural myths surrounding the existence of people with Albinism keep overflowing. He highlights that having contact with an albino is seen as taboo.

My standpoint as a researcher, based on the fieldwork, is that myths about the causes of Albinism are a subject that requires urgent addressing and public visibility, especially to people in the predominantly rural and black South African areas. It appears that Albinism is still a sight of danger and ill karma, and most of the beliefs are based on assumptions. Gabadamosi observes that the assumptions include that a mother is infected with albinism through seeing or touching a person with Albinism or a mother sleeping with the “wrong person” or a “tikoloshe”. So the beliefs are that Albinism is contagious as opposed to hereditary and its source is infidelity. Regina Mary’s story also attests to this stereotype. Her black mother was asked if her husband was white, while her husband questioned if she had engaged in intercourse and was unfaithful to him with a white man. It appears that people are so brainwashed that a light in complexion child is born from an intimate sexual affair with a white person. In the film *Xakhubasa: The White Pride* (Perros and Munro:2013), a child from a white couple is born with Albinism, and it’s discovered that the father has the gene somewhere in his lineage. This bears testimony to the fact that Albinism is not only associated with Blackness, and that people are misinformed due to ignorance.

Communities in the African Society also classify Albinism as a result of supernatural punishment or a curse. The condition, presented externally, is predominantly seen as malevolent. It is believed that spitting will erase the contagion in the unborn child. It’s no wonder pregnant mothers spit saliva to the ground when they see someone with Albinism. This is visibly expressed in the visual re-enactment of my creative piece, *Beyond Our Complexion*, as MaBhengu, the traditionalist midwife, spits in her jersey after realising that Dinah (acted by Regina Mary) has birthed a baby with Albinism. The mother spitting at the sight of someone with Albinism also affects those who are live with the condition too. Regina Mary has experienced this and says from a young age, most children would spit in their shirts in her presence and refused to share a desk with her. After exploring this phenomenon, it is believed that associating with someone like her would result in the birth of a child with Albinism, or the unborn infant would also change complexion to that of a person with Albinism.

Name calling is a dominant form of “othering”, leading to a sense of rejection that people with Albinism face. They are addressed by derogatory names such as Snow White, inKawu (meaning ghost in isiXhosa), iManki (meaning Monkey in isiZulu), Isishawa (meaning you have been punished in IsiZulu) and even told that they are not human. In the documentary *Xakhubasa: The White Pride* (Robyn Perros and Tassyn Munro:2013), people living with albinism say they are confronted with questions such as whether their mother drank too much milk when she was pregnant, if albinos could read minds and if their mother dropped them in peroxide as a baby? These naïve questions raise concerns around black consciousness in the South African black context with regards to Albinism as a medical condition. Abjection involves a disturbance of order, and ostracises a certain class of people, according to Kristeva. When discussing the Abject, Kristeva (1982:3,4) says “It is not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does not respect borders, positions, rules.” Kristeva is also of the opinion that abjection can explain the structural and political acts of inclusion or exclusion which form the basis of the social existence of people and groups (1982:4). So, based on the stigmas and labelling, there is evidently a large looming debate about the causes of Albinism, and that the marginalisation of this group is still culturally and socially exempted from societies as they disturb the belief that black is defined by other shades except white.

Certain expressions can only reveal feelings, attitudes and emotions of feeling unwelcomed. It is also believed that the body parts of people with Albinism have supernatural powers. In interviews in the documentary *Xakhubasa: The White Pride* (Perros and Munro:2013), people with Albinism say that people ‘feel their skin, pull them and are scared of them’. Gabadamosi says according to the myths, the child is often considered burdensome and ascribed supernatural powers. They will bring wealth to the procurer of their body parts; or through contact bring good or bad luck to an individual.” RG Thomson calls this a demonstration of ‘Freakery’. He points out that ‘freak discourse’ structures a cultural ritual that if it deviates from the usual, intensifies to produce a human spectacle (1996:3). People with a different appearance are often fetishized and treated by the spectator as out of this world. Spectators treat them as negatively capable of performing miraculous deeds. This does however serve as a platform to mock and ridicule them. In light of the above, unfortunately people with Albinism are fetishized in this manner. They are considered lucky charms, and these stereotypes can become so normalised to the extent that even some victims can fall prey to them. Regina Mary attests to the experiences that people used to hold her hands so that they

can go and play the lottery and win. There was even an incident where she asked her uncle if he'd like her hair so that he could win.

Worse, discrimination also contributes to people with Albinism displayed as freaks because of assumptions that they do not die, but dematerialise. The film *Powder* (Victor Salva: 1995) profoundly touches on death and freakery. Reed is a lead character with a condition similar to Albinism and is rejected by his father from a young age due to his unusual pale appearance. In the scene, Reed is supernaturally elevated and carried by lightning to the heavens after being kept in the basement all his life because of his physical condition. This suggests the idea that people who look different indeed do not die. In *Powder*, Reed is regarded as a *freak* as his journey evolves to that of an outsider because of his external appearance and incredible intellect, telepathy and paranormal powers. This is also shown as director Victor Salva reveals that Powder has an instant insight into his tormentors. He can listen to people from the inside, and knows the school bully was abused as a child. Yet Reed, also known as Powder's empathy draws only insults as the bully calls him *Light Bulb*. Statements such as "You keep that thing on a leash" and his enemies taking him out into a storm, hoping he will attract lightning seem to prove "this". This affirms his freak, abject status. Regina Mary says nobody disappears; they are human beings who feel, get sick and also die. These myths are surprisingly, held by both the learned and uneducated. It is expected that people who are educated should be more knowledgeable about the facts and aware of the myths. Everyone eventually dies.

It is also unfortunate that on the African Continent, the body parts of people with Albinism are hunted and sold for exorbitant amounts of money. Their limbs are believed to have healing remedies that can even cure terminal diseases such as Aids, and the intrusions have to be violent. The more an albino screams during the attack, the stronger the magic and thus the higher the gain. This is a phenomenon that is predominantly practiced in central African countries such as Tanzania. While others want their body parts to obtain wealth, the contrary behaviour is to not touch them as it is ominous. These contradictions in beliefs create binary forms of depicting people with Albinism. Both extremes; good and bad creates confusion in societies about their reactions to people with Albinism, which fuel the discrimination towards them. The binary representation of this *freak* is that according to Salva, while Reed's abilities mark him as a special, they also make him an outcast. The constant bullying also instills fear within Reed, resulting in his being ostracized from the society and left to exist in isolation. These conditions label Reed a freak. Freaks according to Grosz (1996:56) are not just unusual

or atypical; more than this is necessary to characterize their unique social position. The freak is thus neither unusually gifted nor unusually disadvantaged. He or she is not an object of spectacle or pity, but is a being that is considered simultaneously and compulsively fascinating and repulsive, enticing and sickening. Sadly, people with the Albinism have to be protected and housed in safe havens, to protect them from perpetrators. Ultimately, people with Albinism want to rather be seen from the “inside” than the “outside”.

7. Identity and Integration in South African Society

Pieter Hugo's Photography- *The Albino Portraits*

Societies lie at the core of shaping our identities. Through this research I have observed that they form a critical part of how we view ourselves. Ignoring award winning South African photographer, Pieter Hugo's work would be doing an injustice to this research paper as he has made a significant impact on the manner in which Albinos are viewed globally. The astounding part about his work is that Hugo claims to mirror himself through his work, when covering marginalised people living on the peripheries of modern South African society.

According to Hugo, the initiation of the project *Looking Aside* (2006) was influenced by an earlier body of work titled *Margin* (2002) included a portrait of an orphaned albino boy standing next to a birdbath outside his orphanage. He was captivated by the picture and the role albinism plays in South African society. So Hugo engaged on a quest that would address views on albinism and photographed it as extraordinary and ‘other’, as he was battling with his own identity and felt ‘othered’ as a white South African on his own continent. He says "My homeland is Africa, but I'm white. I feel African, whatever that means, but if you ask anyone in South Africa if I'm African, they will almost certainly say no. I don't fit into the social topography of my country and that certainly fuelled why I became a photographer."(*The Guardian*:2008) From this, it becomes evident that this series was a journey with personal intentions. One of the images in the series of *The Albino Portraits* (Pieter Hugo:2004) is a picture of the photographer himself. This raises the question of whether Hugo regards himself as an outsider as well, and relates to the perceptions on Albinism as outcasts.

As a white male in South Africa, Hugo suggests through the photographs and the series that he has similar challenges to people living with Albinism. When I viewed the pictures in his series, many of which I have included in my film, this claim is unfounded. People with Albinism have serious issues with acceptance, than a White South African male from Cape Town. With the history of white privileges and black oppression, Hugo has attempted to appropriate Blackness as a margin that is politically unfounded and opportunistic. South Africa has a painful past with white supremacy, making Hugo part of an elite group. In my opinion, he is only using this claim as a way to lure South African historians or a different class that would not politically criticise his work.

The construct of his photographs is probably where the essence of my criticism lies, and raises most of the varied reactions regarding this series. An interesting revelation is that Hugo certainly manages to capture people we usually prefer to turn away from; people with Albinism. According to Leah Ollman "The two most common responses when coming across people with physical anomalies are to stare too bluntly or look away too quickly. Both reactions are awkward and neither registers a high score in the humanity department." (2007:1). This is evident in Hugo's work. One either looks away in rejection or completely zooms in to unravel what really lies embedded in the photographs.

Lighting and background play an essential role in the interpretation of photography. In the portraits, Hugo's subjects are photographed under crisp light and behind a blank background. Their eyes also directly meet the viewer's. With this strategy, Hugo seemingly forces us to confront ourselves, our preconceptions and prejudices. This presentation makes us explore the awkwardness associated with our encounters with others who are unusual, for reasons of albinism according to societal standards. A different perspective is that Hugo's expressions in his work create a sense of uneasiness in the viewer's mind. One wonders about whether he enjoyed photographing the subjects as the "objects" in his work, and if the people photographed were voluntary participants. This could have been an unpleasant journey for the viewer. On the other hand Sean O'Toole (*Art South Africa*:2004) writes "Instead of speaking in words that court emptiness and the void, Pieter Hugo's images confront viewers with the necessity of speaking in a new vocabulary, one that celebrates the fullness of being." Could this be an interpretation that has the potential to change perceptions, and should one perhaps try and explore the vocabulary or mannerisms in which people with albinism should be viewed? I am still of the view that although Hugo's work creates opinions, he is very disconnected from associating, or even inherently relating to people with Albinism. Also,

people cannot only be described or defined by just their mere appearance. It would be interesting for those photographed to express their views, about whether Hugo captured them “accurately”, and the feelings that the pictures evoked to the human subjects of his work. I deliberately used a montage of people with Albinism towards the end of my film, to give them a different active voice compared to the deafening silence and presumptuous, intensely sad approach that Hugo represents in his work. Hugo completely cannot relate to the lives and realities of people with Albinism. He may be struggling with an identity issue pertaining to his white relevance, but is internally and externally appropriating his politics inappropriately, with the aim to mislead even the global community about South African identity politics and the challenges faced by Black and White people. His association with Albinism is controversial and completely insignificant to his world as a white male in a country addressing its oppressive past.

8. Sexual exploitation of people with Albinism

When interviewing Regina Mary about how living with Albinism has affected her sexuality, she unlocks a world that I believe is largely unknown about people with the condition. Through the interview process I was confronted by the recurring gender violence in South Africa. At the tender age of only eight, Regina Mary was sexually abused by a person she called ‘uncle’. At that age she wasn’t aware that the act was rape, not only was she young and oblivious to the act, but after the offence, her perpetrator offered his victim sweets, and asked her not to tell anyone about it. “It was almost like he asked me to come and sit on his lap as an uncle would do to his niece, and I did that. I had recognised that my underwear was wet so I didn’t know what was happening or what had happened to me coz he made me sit on his lap.” Then Regina Mary’s perpetrator offered her sweets. It was only after the eight year old removed her underwear and placed it in the bathroom when her mom found it, with the man’s semen on it. The child got a beating from her mother, and this incident was never discussed again. Regina Mary did not know or understand that she had just become a victim of rape, and learned of this when she was older.

In a democratic South Africa where the political structure is constitutionally more inclusive, the narratives of people living with Albinism has emerged more visibly from this research. I was awakened to the reality that there are increasing numbers of women with Albinism

experiencing sexual exploitation. The belief that having sexual intercourse with a female person with Albinism will make the male wealthy or cure him from any ailments is on the increase.

Sadly, even young children are being sexually assaulted for such rewards, and the numbers of these incidents are on the increase. Unfortunately, sexual favours are sometimes performed by vulnerable and innocent children who are promised a reward in return. Thomson (1996:17) writes that such explorations are part of Freakery and how society exploits freaks is part of their history of being displayed. For someone to use a person rejected by humanity through sensationalizing stories that makes his or her body not only a cultural spectacle but a sexual one, and who believes that intercourse with "this spectacle" will bring you good fortune is freakery. The act of obtaining sexual favours represents a token of the anxieties and aspirations of a society's intent upon publicising the freak's private body.

Grosz' concern is about the dual horror and fascination others have toward those they label freaks. She says that "the initial reaction to the freakish and the monstrous is a perverse kind of sexual curiosity. People think to themselves: How do they do it? What kinds of sex lives are available? There is a certain morbid speculation about what it would be like to be with such persons, or worse to be them." (1996:64) Men request female prostitutes to recruit women with Albinism. Women and children with Albinism fall prey to prostitution, lured and used as sex objects by female prostitutes to be used by men. Often, they agree as this is also a way for those with Albinism to feel a sense of belonging in societies who are hostile towards them. Regina Mary's home was close to the homes of three prostitutes who were friendly to her. She enjoyed the attention, as they too told her that she was beautiful. At night, they engaged her in orgies with various men. "They would have their clients over for private sessions, have sex in front of me and show me how to strike a man's penis up and down. I remember it was the same time my teacher was busy with me, when I was ten. I thought it was fine but it carried on to where I could touch. If I wanted people to like me this was exactly what I had to do to get attention." Ultimately the child got so used to this behaviour that she would even make sexual advances to the gardener outside, asking him if he also wanted to sleep with her. At first he would be reluctant, but ultimately agree to have intercourse with the child. Although Regina Mary, initially didn't want to believe that these incidents were as a result of her condition, she also admits that perhaps this could be the reason.

Acts of sexual molestation should be condemned. Former South African President Mr Thabo Mbeki in his speech condemned these acts, remarking that they were 'barbaric acts of savages' who just want to strip children of their rights. Mbeki (2001:1). Mbeki also emphasised that children are introduced to thoughts that older people are not their protectors. Similarly, Korbin says child sexual abuse is best conceptualised as the disruption of expected roles, relationships and behaviours (1990:44). It is often said that once a person has been sexually assaulted, the first incident spirals a succession of the same, if not similar events. In grade four, Regina Mary's battle in the classroom was that she couldn't see the teacher's writing on the blackboard due to her visual impairment. Her visual impairment is clearly depicted in the film, as her French class teacher ridicules her for not participating in the lessons. Eventually, he would request that she stand next to his desk and read from his textbook. This was always an opportunity for him to molest her, causing her pain by inserting several fingers into her vagina. This was often followed by praise about her beauty and intelligence, followed by an instruction for her not to tell anyone about the molestation. Sexual molestation of people with Albinism remains an under researched area. It is however very disheartening that people are still of these beliefs, especially so many years into the democracy of South Africa. The white-albino population is not the concern in this research, since my concern was to understand the black experience of this "whiteness" in South Africa.

9. How Film and Photography Portrays People with albinism

The creative component of this study depicts and explores the portrayal of people with Albinism. In both the film and her audio interview, Puleng shares strong sentiments on what she declares is a "sad reality". She says marginalised groups are not afforded the platform to relate their own stories, yet they have voices and experiences that must be told. In the film, she speaks about how her show *Bophelong* is breaking barriers around these minority groups of people. The television show moves away from the typical and a stereotypical portrayal of what the person is apparently like or what their life should be. Douglas Kellner (1995:7) agrees that radio, television, film and other products of media culture provide materials out of which we forge our very identities, our sense of selfhood, our notion of what it means to be a male or female, our sense of class, of ethnicity and race, of nationality, of sexuality and of 'us' and 'them'. Currently in the South African visual media context, not enough attention is being given to this marginalised group. If media is a tool that is meant and promises to

equally represent people of all colours, then we are marginalising people who look and are differently abled, as they would prefer to be referred to, and are misrepresenting their stories by narrating on their behalf. For people with albinism in particular, this doesn't present a true reflection of their lives and experiences. They want to tell their own stories, in the manner which best embodies them.

In light of the above, Elliot Gaines (2010:93) observes that culture, ideology and myth help to describe how groups of people understand aspects of the world in which they live. People with disabilities are often stereotypically treated as freaks in the media, and say it's rare that they are presented as champions. If a person with disabilities excels in anything, it is presented as unexpected, heroic and exceptional. Puleng says the narrative doesn't allow them to tell their stories from their own perspectives. She highlights that "If you are noticed for being different you are always seen as the rare individual who's doing exceptionally, because people are actually not expecting you to be that way." Puleng also feels that in the South African context, even when people with Albinism are profiled in the media, there is still an element of undermining their potential, taking away much of their credit. Stuart Hall says this is fetishism (1997:268). The representation allows a double focus to be maintained in the looking and not looking which is an ambivalent desire to be satisfied. What is declared to be different, hideous, 'primitive', deformed is at the same time being obsessively enjoyed and lingered over because it is strange, 'different', exotic. This confirms Puleng's concerns about the views of her spectators. The docciefilm has however created a platform to showcase Puleng presenting her television show. Regina Mary is also of the belief that most stories about people with Albinism are negative and portray them as victims instead of heroes. "I think most stories about people with Albinism are stories about oh we're getting chopped, your hair can do muthi, you were raped because of albinism." She says people with Albinism are often typecast into positions and characters that they are discontented with, while she wants to be known as one who tells the story of her life on stage and a motivational speaker. They want roles that don't stereotype and attract the audience to sympathise with them. This research has allowed Regina Mary to showcase her talent by giving her the opportunity to re-enact some of the scenes in the film. She re-enacts the classroom scene where she is molested by her educator, and of the woman who gives birth to a child with Albinism in a shack who is soon forced to flee the settlement with her baby, because of fears that they will be "othered" and are unaccepted by society. The re-enactments have granted Regina Mary a platform to narrate part of her story through a visual medium, a skill that she

yearns to harness and authenticate the narrative of people with albinism. It is therefore imperative for media to start using interviews like of Puleng's when they are positively newsworthy. People with Albinism also want to be seen as survivors, and it appears that currently, the media is not doing much justice to them in this regard.

Raimi Gabadamosi (*Mail & Guardian*: 6 September 2013) is of the opinion that reports on people with Albinism influence stereotypes. Headlines, captions and the actual details of the story often don't report on positive incidents. There seems to be a lack of interest from the media to cover the heroic stories of people who have overcome these adversities. Regina Mary has appeared in a series called the *Linken's Claim* and her character was not that of a woman with Albinism, but that of a Chef, also a gossip queen. She has also acted in a Mzantsi TV bioscope, *In my Misery*, where she played a PA. For Regina Mary, these roles enhance the way she would like people with disabilities, those with Albinism in particular to be observed on visual media as socially integrated. It makes their narrative more powerful. These two women living with Albinism have thus become inspirational as mentors and role models to also change some perceptions of albinism.

10. Media Culture towards People with Albinism

Puleng recollects some of her difficulties when she first moved to Johannesburg and enrolled in Drama Studies at Wits University. Inexperienced yet very excited, the reception from fellow students was distasteful, because of her appearance. She was even asked if she had ever actually seen someone like herself on television, acting or presenting. Many would utter that being on screen requires working with cameras, lights and that the harshness of the lighting would not present her as the 'ideal person' under the lights. Puleng says "If they were not so curious, my friends in varsity made it clear and asked girl what the hell are you doing here, you don't even belong here". This treatment suggests that even from her introduction to drama studies, Puleng was already 'othered', abjected and stereotyped as she would not belong due to her different appearance. According to Hall (1997:258), "stereotyping deploys a strategy of 'splitting'. It divides the normal and the acceptable from the abnormal and the unacceptable. It then excludes or expels everything which does not fit, which is different." Puleng was stereotyped as this form of representation repels anything which does not belong.

The rejection continued as casting agencies constantly reminded her that with her squinted eyes wouldn't qualify her for acting roles and that perhaps if she corrected them could be considered. Furthermore, circumstances became even more challenging when she proposed a television programme, *Bophelong* at the South African Broadcasting Corporation. Puleng alludes to the fact that most colleagues were fond of her, until she announced that she wanted to anchor the show. Kellner (1995:7) states that media stories provide the symbols, myths and resources through which we constitute a common culture through which we insert ourselves into the culture. This reception confirms that Puleng would not be accommodated into this culture, as she did not fit the perceived social or media requirements. Ultimately, through perseverance she forced her way, against all criticism, and now hosts the show. Still, she has to go an extra mile to remain on screen and says "it's the perception of most people in high positions and the SABC News department. They really are uncomfortable with someone like me doing what I'm doing. For years they've known the newsroom as they have known it, and here I am expecting them to increase the font on the autocue and bring it closer". This treatment attests to the fact that the media, if not its employees such as producers and crew, is not yet completely accepting of people with Albinism. The situation is so dire, that Puleng says that the popular belief in the newsroom is that she obtained the position through someone 'doing her a favour'.

Similarly, Regina Mary faced rejection at the beginning of her acting career. She embarked on a drama and acting course, where the Director of a well-known SA drama series, *Hopeville* was present. On the final day of class he pulled her aside, and mentioned that he hadn't raised her Albinism in class. He then asked Regina Mary if she was an Albino, a term which people with albinism detest being addressed by. He continued to say, "I'm not saying you can't do it, but I'm saying no director will wake up and write a script about you, so it's going to be very hard. But you are good, bubbly and well spoken." According to Regina Mary, although he weighed both advantages and disadvantage, all she heard was "you're an Albino and it's not going to work". Months later, what seemed to be a miraculous incident happened to the disheartened drama enthusiast. A phone call from writer and director Arthur Molepo, desperately wanting to see her changed her life. Mr Molepo, according to Regina Mary said he had written a play 30 years ago and was not ready to put it on stage, and even better needed her. In an interview with Regina Mary, she says Mr Molepo's words were "I don't care whether you know acting or not, I will train you with anything you need to know." This incident transpired after Regina Mary had applied at The Market Theatre in Johannesburg

and in her words, “I did a good piece for them, and they loved it, they said you are so beautiful and you can sing.” Unfortunately she was rejected as she couldn’t read a script due to her visual impairment. Fortunately, Mr Molepo then went to the Market Theatre describing a girl who perfectly fitted Regina Mary’s appearance, and she never looked back. “It was my first time on stage, my first job ever, literally this man drew a stage with a chalk on the floor for me to see entrance and exit. For the first time I was on stage, next to great actresses like Simphiwe Nkosi. I was paid for the first time”. The preconceptions and judgement of people in the Film and TV, or Visual Arts industries have the potential to determine the fate of people with albinism. If perceptions were altered, this would greatly assist this marginalised group in their endeavour to break barriers and stereotypes around Albinism in visual media. Film and television is slowly progressing with accepting and accommodating people with Albinism. Although a handful of artists with Albinism are visible in mainstream media, social networks and in the theatre, changing socio-cultural perceptions is slow because of access to the mediums and prevailing cultural misconceptions. As a researcher, I am hoping that *Beyond Our Complexion*, in film format will play an instrumental role in changing the face of how People with Albinism are represented in visual culture in the South African context.

11. Beyond Our Complexion-The Film

Beyond Our Complexion is a documentary with aspects of enactments which encapsulates the challenges faced by people living with Albinism. It tells the story of the protagonist Regina Mary Ndlovu who lives with the condition. Through her personal experiences, the film uses enactments to recreate and relate some of Regina Mary’s most daunting encounters with Albinism. Regina Mary’s narrative, in her own voice, is a representation of many aspects about the condition that is either unknown or unexplored sufficiently in the broader society more generally. The film begins with a monologue which provokes the viewer’s thoughts about the sight of a person living with albinism but is also offered in a way which challenges the dominant representations of people living with the condition. I placed a photograph of Regina Mary amidst a background which makes her appear angelic, innocent and without fault. But the monologue interrogates the viewer to ask questions about the image that they are observing. This imagery and narrative addresses how people with Albinism regularly feel when looked at in a society that stares at them with disgust, wonder and judgement making them feel unwelcomed and misplaced.

The film continues to expose us to challenges faced by people with Albinism. We witness Regina Mary troubled by short sightedness which restricts her from reading what's on the board, resulting in being ridiculed by fellow learners for her inability to participate in the classroom activities. The skin is also a crucial aspect to highlight, as according to Regina Mary, it is their worst enemy. I used relevant moving photography and underlying sounds of fire and heat to create a sense of the burning and peeling of the skin.

The film also speaks to hardships of sexual molestation. It comes across in the scene with Regina Mary being molested in the classroom by a teacher. This raises awareness to the plight of child abuse towards this marginalised group, as Regina Mary initially thought the molestation was from people who appreciated her skin and would protect her from being bullied or being ridiculed. This inhumane behaviour for selfish gain due to superstitious beliefs is perpetrated on children, fooled to believe that it is for favourable reasons. It highlights a great need and opportunity for research which will enable the vulnerable to be protected against sexual assaults.

Regina Mary uses the birth scene to provoke the viewer. The narration highlights that people with albinism are not embarrassed about giving birth to children that look just like them. Ultimately they are mothers too with the same maternal instincts. They do however fear the world's reception of their young. Spitting at the sight of someone with Albinism is a common practice, from those who believe that spitting frees one from the curses associated with an encounter with someone with the condition. The act of spitting is evident in the birth scene as the midwife spits in her shirt, uttering that God has forsaken the woman who has had the rare child. She also displays her disgust by leaving the mother with her baby in the shack, and leaving them unattended. Communities become hostile and ostracise Albinism, as a result the mother and her child are seen fleeing the informal settlement, in search for a better life.

A monologue also encapsulates how people with Albinism wish to be treated. Regina Mary speaks about how they also want to be treated as brothers and sisters, that their body parts will not make anyone rich, that they love their complexion, their albinism and just want to be given opportunities to display their capabilities. Regina Mary's voice represents the voiceless multitudes with similar experiences, who want exposure on social media to be noticeable for simply being human.

The use of ambient music and sound effects, colour grading and other editing techniques were appropriately selected to bring light to the feelings associated with the visuals, allowing

the viewer to engage in the story visually and audibly. I allowed Regina Mary to view the film before finalisation, and I was deeply touched as tears streamed down her cheeks. "This film touches on everything I want to address about Albinism. The photographs you used are of those who I often look at and say, I'm coming to save you." This reaction gave me a sense of achievement and gratitude as this was the reaction I had hoped to get from her. Not only was my mission to raise awareness about Albinism, but to have also done justice to the desires of Regina Mary, a real-life character who has favourably allowed me as a producer and journalist to use her story as a tool to further empower others. It has emerged that visual culture and various social media platforms need to urgently change perceptions in the manner in which they have been presenting the stories of people with albinism. So much more remains unearthed beyond their complexion, and they wish to be given platforms to live and express themselves.

12. Conclusion

The film was an instrumental platform to incorporate all the aspects required to fulfil the demands of this research. The paper was a reflection of how theory and real live interviews merge in order to get a clearer understanding of the subject. I set out to explore the manner in which people with Albinism are represented in visual culture, and found more than I had expected. Meeting the characters revealed that even I needed to change my personal perceptions on people with albinism as I knew very little about them. Regina Mary and Puleng as main testimonials played an essential role in unpacking some of the mysteries about Albinism. It emanated that sexual exploitation was an area that needs to be addressed, as children are exposed to it with the belief that the perpetrators will become rich through sexual contact with them. People need to be better informed about these myths and the extent to which they adversely affect this marginalised group. Perhaps attention needs to be paid more on teaching children with albinism about the signs and dangers of being inappropriately touched for material gain. Self-appreciation and a high esteem also needs to be introduced to infants with albinism to avoid this scourge.

I approached selective areas around the challenges of people living with Albinism. I focused on the representation of this often "othered" group of people through interviews, referring to other people with albinism such as Raimi Gabadamosi and Sibonakaliso Mpisi. I also

afforded them the platform to express their concerns. From my findings it has emerged that people with Albinism are not visible enough on media platforms. From the fieldwork, I have come to understand the seriousness of this issue, and the importance of accepting them as our own, regardless of their physical appearance. Stuart Hall suggests that 'difference' is ambivalent. "It can be both positive and negative and is necessary for social identities. At the same time it is a threatening of negative feelings, of splitting, hostility and aggression towards the 'Other' (1997:238)". Mockery is a prevalent negative reaction towards people with Albinism, and the media can serve as a pivotal tool in addressing and attempting to eradicate stigmas and myths around Albinism. It has also surfaced, through theories of representation, that societies need to be better informed about Albinism and its causes. But there is hope as Puleng and Regina Mary have risen above the odds as great examples of role models and mentors, who advocate for fairness and a better presence in the media for people like themselves and other marginalised groups. They have chosen to tell their own stories and must be treated as protagonists, fully capable of living normal lives and doing most of what abled people can do.

As a journalist and producer, I have also observed that the media needs to engage in conversations about how to improve technical efforts and equipment to ensure that people with Albinism are catered for. There needs to be continuing dialogue about how cameras and lighting, just to name a few, can accommodate their special requirements. This way, visual media would have played its role at ensuring that our mission as film and media creatives is well executed, by presenting people with albinism in a fair and favourable manner, beyond their complexion.

13. References

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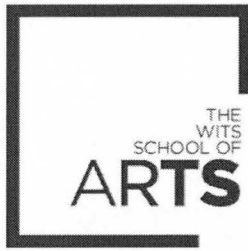
Filmography

District 9, 2009. Film. Directed by N. Blomkamp. South Africa: Tristar Pictures: 112min (PN.1998.3 BLO DIS)

In the Shadow of the Sun, 2012. Film. Directed by H. Freeland. Netherlands: British Broadcasting Corporation: 1h 28min

Powder, 1995. Film. Directed by V. Salva. USA: Walt Disney: 111min

Xakhubasa: The White Pride, 2013. Film. Directed by Robyn Perros and Tassyn Munro: 24 min



17 May 2018

Final Supervisor's Report confirming completion of revisions

STUDENT: Didintle Mookeletsi

Student Number: 769336

Didintle Mookeletsi submitted her final report in November 2017 and her examiners reports were delivered to her at the end of April 2018.

I am pleased to confirm, as her supervisor that she has completed the revisions that were required from the external examiners reports to satisfaction .

Her research project "Beyond our complexion: Albinism in visual culture" now has the revisions that can be submitted as the final research for archiving at Faculty and the university.

Please note: that this research has an accompanying film "Beyond our complexion" which should also be archived with the written research report.

Sincerely,

Jyoti Mistry
Professor



Wits School of Arts - Film and Television

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