

**Representation of Albinism and Persons with Albinism in Narratives from East and Southern Africa**

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## **Declaration**

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## **Dedications**

For my children and marginalised individuals.

## **Abstract**

This study examines representations of albinism and characters or subjects with albinism in a selection of literary and cultural texts set in, and from, East and Southern Africa. The analysis brings together contemporary fictional, auto/biographical, and short documentary film representations produced between 2009 and 2020, a period marked by an increased production of texts dealing with albinism in the African context. The study considers how characters or actual people with albinism (PWA) and historical, socio-cultural, and medical perceptions or discourses of albinism are narrated, portrayed, and framed to focus on the manner in which issues of agency emerge in the representations. Given the variety of issues that intersect with albinism in the texts studied, my study is a multi-disciplinary and cross-cultural reading of the representations of albinism and individuals with albinism. My research converses with theories and germane criticism from a scope of disciplines and fields such as disability studies, gender studies, (African) philosophy, narrative theory, and life narrative studies. My research establishes that literary and cultural texts are a site where public and private agency of subjects and characters with albinism is (re)configured and where various perceptions describing albinism and persons with albinism are (de)constructed and (re)conceptualized.

## **Ikisiri**

Utafiti huu unahusu usawili wa wahusika wa ulemavu wa ngozi na uelewa kuhusu ulemavu wa ngozi katika matini teule za kifasihi na kiutamaduni zinazozalishwa na/au kutoka Mashariki na Kusini mwa Afrika. Uchambuzi huu unahusisha kazi za Sanaa za nyakati za sasa na filamu fupi zilizozalishwa kati ya mwaka 2009 na 2020, wakati ambao kulikuwa na ongezeko kubwa la matini zinazohusiana na ulemavu wa ngozi Barani Afrika. Utafiti umezingatia jinsi wahusika au watu halisi wenye ulemavu wa ngozi wanavyochora katika kazi katika fasihi, mitazamo ya kihistoria, kiutamaduni-jamii na kitabibu au vilongo kuhusu ulemavu wa ngozi vinavyosimuliwa, kuwakilishwa na kupewa mwega kuhusiana na jinsi watu wenye ulemavu wa ngozi wanavyopewa nafasi katika uwakilishi. Kutokana na masuala anuai yanayohusishwa na suala la ulemavu wa ngozi katika matini zilizochunguzwa, utafiti huu unaonesha usawili mtambuka kiuga na kiutamaduni wa ulemavu wa ngozi na watu wenye ulemavu huo. Utafiti huu unaongozwa na nadharia na tahakiki kutoka nyuga na mawanda mbalimbali kama vile tafiti kuhusu ulemavu, jinsia, falsafa (ya Kiafrika), nadharia ya usimulizi na tafiti kuhusu simulizi za maisha. Utafiti huu unaweka msingi kwamba matini za kisanaa na za kiutamaduni ni muktadha ambamo wahusika wenye ulemavu wa ngozi wanachorwa na mitazamo mbalimbali kuhusu ulemavu wa ngozi na watu wenye ulemavu huo huibuka, kujijenga na kuundwa upya.

## Opsomming

Hierdie studie ondersoek voorstellings van albinisme en karakters of subjekte met albinisme in 'n verskeidenheid literêre en kulturele tekste wat in, en vanuit, Oos- en Suider-Afrika afspeel. In die ontleding word voorstellings van hedendaagse fiktiewe, outobiografiese en/of biografiese en kort dokumentêre rolprente byeengebring wat tussen 2009 en 2020 vervaardig is, 'n tydperk wat deur 'n verhoogde produksie van tekste oor albinisme in die Afrika-konteks gekenmerk word. Die studie ondersoek hoe karakters of werklike mense met albinisme (PWA) en historiese, sosio-kulturele, en mediese persepsies of diskoerse oor albinisme vertel, uitgebeeld en aangebied word om vas te stel hoe kwessies van agentskap in die voorstellings na vore kom. Gegewe die verskeidenheid kwessies in die studietekste wat by albinisme aansluit, is my studie 'n multidissiplinêre en kruiskulturele lees van die voorstellings van albinisme en individue met albinisme. My navorsing tree in gesprek met teorieë en tersaaklike kritiek uit 'n wye verskeidenheid dissiplines en velde, onder meer gestremdheidstudies, genderstudies, (Afrika-)filosofie, narratiewe teorie, en lewensverhalende studies. My navorsing bevestig dat literêre en kulturele tekste 'n plek is waar openbare en privaatagentskap van subjekte en karakters met albinisme (her)gekonfigureer word en waar verskeie persepsies oor die omskrywing van albinisme, en persone met albinisme, ge(de)konstrueer en (her)gekonseptualiseer word.

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## CHAPTER ONE

### “THE ALBINOTIC BODY”:<sup>1</sup> CORPOREALITY, TRADITION, AND TEXTUAL REPRESENTATIONS

#### 1.1 Introduction

"THE ALBINO'S VOICE"

I get no respect, but pig treatment

Just because, of a lack of a skin pigment.

Is a book, only a book by its cover?

knowledge lies in the book's contents, not its cover.

What ever happened, to the spirit of humanity.

I guess it only resides, in the hearts of the minority.

Monsters and vampires, covered in human costumes.

Hunt, kill and sell my body parts and blood for fortunes.

Hear my cry, owe children of the sky.

Here I ask myself, but never understanding why.

Life has served my kind, with such unfairness.

[Where] my kind is murdered, with such brutal murkiness.

We are all different, Africans, Asians, and Latinos.

Now why are we so oppressed, as albinos.

We have a lot to learn, from the birds of the sky.

Never had I heard of eagles and owls, discriminate against  
flamingos. — SIYABONGA KHOLOLWAKHE NZUZA<sup>2</sup>

“At the seam where body joins culture every construction of the  
body begins and ends. On the efforts of cultures to hide that seam,  
every oppression ends.” – Mark Jeffreys (Cited in Fraser 73)

At the crux of Mark Jeffreys' comment is the idea that culture or tradition scripts and rescripts bodies. Within any given culture, stories about bodies are produced, circulated, and accepted. Stories can create norms which may eventually compel people to conform to certain patterns of living. For example, the schism between people deemed normal on the one hand, and on the other hand, those designated as abnormal (with, for example, peculiar bodily conditions) exemplifies how bodies are culturally assigned meanings. From these assigned meanings

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<sup>1</sup> The term is from Elvis Imafidon's "The Other as Unbeautiful: Analytic Somaesthetics, Disgust and the Albinotic Body in African Traditions". *African Somaesthetics: Cultures, Feminisms, Politics*. Edited by Catherine F. Botha. Brill. 2020.

<sup>2</sup> See <https://letterpile.com/poetry/ALBINO>

certain bodies or persons are seen as superior. Thus, the question of who one is in relation to others, and how people treat or consider one's identity is, as Jeffreys' comment suggests, culturally determined and/or critiqued. In relation to this idea, this study examines selected literary and cultural texts (in written and filmic forms) to explicate how bodies of people with albinism, "an inherited disorder characterized by a reduction or absence of melanin in the hair, skin, and/or eyes" (Kirkwood 13), are culturally assigned and re-assigned specific meanings.

The current study examines representations of albinism, characters, and persons with albinism (sometimes referred to as PWA)<sup>3</sup> in a selection of literary and cultural texts from East and Southern Africa (Tanzania, South Africa, Zimbabwe, and Rwanda), produced between 2009 and 2020. This was a period marked by an increased publication of texts dealing with albinism in the African context, deemed "a response to the number of murders and mutilation of [PWA]" (Lipenga and Ngwira, 1473). This research comes as an intervention to explore how representations of subjects and characters with albinism in the texts studied "configur[e] them to fight back against" (Lara 5) their frequently negated identities. As a point of departure, this exploration not only considers how "albinic identity" (Miller 4) or historical, socio-cultural, and medical perceptions and discourses of albinism are narrated, portrayed, and framed, but particularly delves deeper into the manner in which issues of agency are configured and reconfigured in the selected texts.

The selection of texts is taken from different African cultural settings and genres. The first analytical chapter (Two) focuses on two fictional narratives in the form of children's novellas: Nahida Esmail's *Living in the Shade* (2011) and Elias Mutani's *Human Poachers* (2016), both set in Tanzania. In the second analytical chapter (Three) I analyse two novels for adult readers: Petina Gappah's *The Book of Memory* (2015) and Unathi Magubeni's *Nwelezela: The Star Child* (2016) set in Zimbabwe and South Africa respectively. The third and final analytical chapter (Four) examines four selected life narratives in written and filmic forms.<sup>4</sup> These include

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<sup>3</sup> In the texts I study, people with albinism are mostly referred to as albinos, but Imafidon clarifies that "Persons with albinism [...] passionately hate being called 'albino' for obvious reasons [...] the word albino concentrates on disability of persons with albinism without recognizing that they are persons, and this continually perpetuates the idea that they are not persons" (*African* 112). Given such, Imafidon uses "PWA for a person with albinism and PWAs for persons with albinism" (112). This thesis agrees with Imafidon's observation but uses PWA to mean both a person and/or persons with albinism as preferred by some organisation that deal with PWA's concerns such as "Under the Same Sun" (see <https://www.underthesamesun.com/sites/default/files/WHY%20WE%20PREFER%20THE%20TERM%20PERSON%20WITH%20ALBINISM.pdf>). When I refer to a person with albinism in the studied texts, I refer to a character with albinism or subject with albinism.

<sup>4</sup> I use the terms "life writing" and "life narrative" as suggested by Sidonie Smith and Julia Watson in *Reading Autobiography: A Guide for Interpreting Life Narratives* (2010). These terms propose a usage "more inclusive of the heterogeneity of self-referential practices"; whereas "*life writing* [is] a general term for writing that takes a life, one's own or another's, as its subject", "*life narrative*" is used "as a general term for acts of self-representation of

two autobiographical accounts from the collection *Looking Inside: Five South African Stories of People Living with Albinism* (2009),<sup>5</sup> edited by Zukiswa Puwana and Shirley Gunn: Vuyiswa Kama's "Dare to Dream" and Mandisi Bongelo's "I am a Human – Flesh and Spirit", as well as two short *YouTube* documentaries, similarly titled *I Will Never Give up on My Albino Children | BORN DIFFERENT*, but abbreviated and numbered by me according to dates uploaded on *YouTube* as *IWNGU-1* (8 October 2020) and *IWNGU-2* (23 October 2020). Both documentaries are set in Rwanda and have been produced by *Afrimax* TV. The fictional and autobiographical texts studied in this thesis are in English while the two documentary films are in English with interviewee comments in Kinyarwanda, translated and subtitled in English.<sup>6</sup>

I selected these texts because, although they are different in genre, form and medium, they all originate from East and Southern African areas. They are written and produced by people or organisations from these regions, and they entail representations of the marginalising experiences of characters and subjects with albinism in various socio-cultural contexts. They further share thematic concerns associated with vulnerability, disability, identity politics, education, superstition, and social relationships, to name but a few. Albinism, in this context, connects a plethora of disciplinary and discursive concerns, including socio-cultural, humanitarian, and political issues. I consider the chosen texts as relevant materials for achieving my study's aim, for they are rich in modes and methods of narrations which draw attention to contemporary forms of representation that might challenge or support stereotypical perceptions of PWA as, for example, "alien", "other" (Brocco, "Albinism" 230), vulnerable and/or lacking in agency.

## 1.2 Personal Encounters: Motivation for this study

My primary motivation for this study begins with a tragic event experienced during my youth. Growing up in Mara region (Tanzania), I was raised in a culture which storied PWA as "unconventional" or as not-ordinary human beings (Imafidon, *African Philosophy and the*

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all kinds and in diverse media that take the producer's life as their subject, whether written, performative, visual, filmic or digital" (4).

<sup>5</sup> Stories in this collection are in English and are drawn from a collection of "Twenty-one life stories" interviewed and "recorded in 2006 [...], transcribed, and some translated from their original languages into English]" (Puwana and Gunn 2). However, it is not clear whether Kama's and/or Bongelo's stories were translated into English, the language of publication. I had no option but to work with narratives that are presumably or partly translated, given the dearth in the genre. The fact that stories on albinism are mostly in English (original or translated) gestures towards a gap in educational texts in other languages, a publication-related issue, because stories or accounts of albinism are seldom published in African languages.

<sup>6</sup> During the later stage of this study, I struggled to obtain copies of Rutendo Tavengerwei's novel, *The Colours That Blind* (2019) and Nathi Zuma's anthology of short stories, *Excuse My Color: Stories of People Living with Albinism* (2019) in time for inclusion. I also had problems sourcing long documentaries by African directors such as Lupita Nyong'o's *In my Genes* (2009) and thus decided to use short *YouTube* documentaries.

*Otherness* 2, 28-49). These myths and superstitions continue to determine the social relationship of people with albinism and the rest of the community where I was raised. Between 2000-2004, I attended secondary school with a fellow learner who had albinism. He suffered severe discrimination and abuse from his peers who used to call him a ‘*zeruzeru*’, a derogatory Swahili term for people with albinism that means “ghost people” or “zero-zeros” (Stensson 28; Imafidon, *African Philosophy and the Otherness* 47), and so they never reckoned him human, at least that was and still is the case in my culture. While the ghost narrative implies that PWA have immaterial physical bodies, the “zero-zero” suggests that they have limited intellectual capacity. In some African societies, these ideas or “ableist linguistic representations of albinism” (*African Philosophy and the Otherness* 47) have fuelled various superstitions, such as the belief that PWA “do not die, they just disappear” (Lipenga and Ngwira 1472). These terms further isolate or ‘other’ PWA from darker-skinned African bodies, as represented in the texts explored here. In our community, there is also a legend that “*zeruzerus*” are immortal beings. Almost all my friends thought of PWA in this way. However, while at secondary school, I was disabused of these superstitions in profound and (un)fortunate ways. As Imafidon clarifies, provision of “accurate and up to date” information about albinism can enable young Africans to refrain from “wrong notions about albinism”, because education clarifies how these notions “evolved and were sustained by ignorance, and how holding on to them shows ignorance on their part” (*African Philosophy and the Otherness* 116) – the issue to which I return to in Chapter Two on children’s fiction and in the section on *YouTube* documentaries in Chapter Four. Indeed, in Biology class, I learned that albinism is a genetic, inherited disorder, and that PWA are humans irrespective of their skin condition. With such awakened awareness, I began to question cultural or traditional beliefs about albinism, and I deliberately fostered a friendship with my fellow learner with albinism. I wish my story could end here, but alas, in 2007 my friend was murdered, and we heard that his genitals had been harvested for traditional medical practice. I realised that this tragic murder disproved the superstition that PWA do not die: my friend died, and horribly so. The event drove home an awareness of the vulnerability of a person with albinism and, as Elvis Imafidon notes, the unforgiveable, perverse “violent othering of albinism” (*African Philosophy and the Otherness* 112).

Life had another lesson in store. A few years after my friend’s death, I was travelling on public transport, seated next to a woman with twin boys — both with albinism. The one boy clambered onto my lap and remained there for the entire journey. I observed him closely and *recognised* him as a child like any other child, only one with a genetically different skin pigmentation. Subsequently, in 2017, while writing my Master’s thesis on the representation of women in Tanzanian popular music, I came across Nahida Esmail’s children’s novella, *Living in the*

*Shade*. Having read the novella, which features characters with albinism, I thought about how the death of my friend could have been avoided, if only my community had told stories like this one as I was growing up, instead of the ones that perpetuate the myths around albinism. Thus, I became an activist, opposing the prejudiced views of PWA and albinism, on educational and humanitarian grounds. I began to participate in programmes aimed at countering stereotypical perceptions of albinism and PWA. I read fiction and criticism on the topic, dabbled in lyrics, poetry, and playwriting,<sup>7</sup> and decided to pursue my doctoral studies with a focus on representations of albinism and PWA in African societies. Although activism has motivated me to explore representations of albinism and characters or subjects with such condition, I remain cognisant thereof that my role is to pursue a critical, literary-cultural study. Even so, I consider that textual representation of albinism is by itself an ethical call and a form of activism. So, in reading and discussing the selected narratives, my personal philosophies or sensibilities do not solely guide my analysis rather I focus on what the narratives say about albinism and more importantly how they depict issues related to agency of characters and subjects with the condition. For further impartiality, my interpretation of the texts is informed by various scholarly voices and my literary, critical conversation with these voices.

My personal experience taught me that some cultural constructions might pass as truths and become the sole means through which albinism is reviled and PWA are perceived as “other” or not human. There is also a “clamour for human rights for PWA” in literary or cultural discourses upholding agendas such as “albinos can do what other persons can do” or for cultural spaces such as beauty pageants and the aestheticization of PWA (*African Philosophy and the Otherness* 112) which beautify and objectify PWA - the same way women are objectified as beauty queens. In “The Other as Unbeautiful: Analytic Somaesthetics, Disgust and the Albinotic Body in African Traditions”, Elvis Imafidon, an African philosopher who specialises in the philosophy of disability and albinism studies in Africa, writes: “the albinotic body is perceived in African thought as disgusting and this form of disgust is a norm-based form and it is deeply entrenched and perpetuated in African societies” (25). In any case, this construction of albinism is only one of many ways that culture can frame albinism. In his book, *Cognitive Disability Aesthetics: Visual Culture, Disability Representations, and the (In)Visibility of Cognitive Difference* (2018), the scholar, Benjamin Fraser explains the impact culture has on one’s body. Fraser states that “[j]ust as culture has the ability to erase the body [...]it similarly

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<sup>7</sup> I have written lyrics and am writing a play on the topic of albinism. Since this study concerns cross-genre and cross-cultural representations of albinism, I also came to realise the possibilities for future research which should include, for example, an exploration of plays, (spoken) poetry, photographic representations, and can expand to include representations from other African regions and beyond (see Chapter Five).

has the ability to erase the mind” (75). This idea applies to what we generally regard as disability, but it can be extended to allude to how cultural storying of albinism can metaphorically or practically erase or negate the body, corporeality, and intellectual attributes of the person with the condition.

Virginia L. Small’s article, “Sociological Studies of People of Color with Albinism”, elaborates on how albinism is culturally connoted. In this study, Small contends that the condition of albinism “is equated with, and categorized as a blemish, mark, stain, even disfigurement. That is, it is a visual stigma that makes society look at it with suspicion and fear”, hence “[PWA] are also perceived to be inscrutable, sinister, less capable or having a character flaw” (cited in Thuku 6). Small’s observations are made in reference to PWA in the Dominican Republic, but they are also valid in an African context. In Africa, the corporeality of the “albinotic body” (see footnote 1), as my personal experiences and views of scholars cited above show, is figuratively speaking obliterated. The “ghost” and “*zeruzeru*” narratives exemplify how the body and intellectual ability of PWA’s are wiped out, which cements Small’s view that PWA are seen as less capable or as having a fault or weakness in their personal character. As can be inferred from the above elaborations, other constructions of the condition (e.g., as the marker of good and bad luck) are even more problematic. They propagate the verbal and physical abuse as well as murder of PWA. For example, the psychologist Tjitske de Groot reports that “Between 2000 and 2019 in Tanzania, 76 [PWA] were killed and 182 people survived physical attacks.”<sup>8</sup> These abuses are also prevalent in other African regions, and they hail from the perception of albinism as a “spiritual state of being” (Blankenberg 9) and the “beliefs that [body parts of PWA] bring good luck and fortune” (Mwiba 36). The narratives I discuss reveal that in some cases these powers are thought of as demonic or curative but in their study, “The myths surrounding people with albinism in South Africa and Zimbabwe”, Charlotte Baker, Patricia May Lund, Richard Nyathi, and Julie Taylor clarify the ways myths and superstitions can negatively impact PWA. According to these scholars, myths and superstitions regarding albinism and individuals with this condition have fuelled segregation of PWA, because people without albinism resort to social exclusion of PWA for the sake of protecting the society and tragically, these myths have propelled the “ritual killings of PWA for their body parts for use in *muti* or traditional medicine” (177). Such myths and superstitions not only negate the right to life for PWA but also subject them to a state where they are seen as objects of superstition and material commodities for financial gain. Clarifying further, Baker et al. report that “[t]he myths [beliefs and superstitions]

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<sup>8</sup> See *The Conversation*. “Albinism in Tanzania: what can be done to break the stigma” <https://theconversation.com/albinism-in-tanzania-what-can-be-done-to-break-the-stigma-162307>

associated with albinism in South Africa and Zimbabwe have a profound influence on the lives of people with the condition, from the moment of their birth until their death [because they] affect family life and interfere with access to education, employment and marriage” (169). These issues obviously indicate how cultural and traditional constructions of PWA invalidate them as human agents, but, as Jeffreys’ comment suggests, “efforts of cultures” can also “end [...] oppression” (cited in Fraser 8), a point I pursue in this thesis.

Much as culture can negatively affect people’s conception of albinism, it also has the power to reshape those misconceptions. Negative connotations of albinism, “can be challenged by a more scientific and culturally neutral explanation” (Baker et al. 169) which “does not necessarily negate or replace local myths but provides an alternative explanation for albinism” (Baker et al. 179). Literature and cultural texts are proficient in this regard. In “Disability Scholarship at the Seam: The Materiality of Visual Narrative”, a chapter in *Cognitive Disability Aesthetics* (2018), Fraser holds the view that that “[c]ulture [through art and literature] is productive in the sense” that,

it can induce alienation or assert ontological primacy, cleave body from mind or reflect the complicated imbrication of cognition and the physical body. Taken in the artistic sense, culture can both reflect and impact social practice, either enforcing normalcy and the status quo (acting as a conditioning or norming force), or prompting hesitation, sustained reflection, and criticism and ultimately even disrupting normative practice (thus acting as a re-norming or counter-norming force). (75)

Regarding textual representations of bodily conditions, Fraser can be understood as saying that art (literature and cultural productions in the sense of this thesis) can either undermine or uplift those whom it depicts. Reflecting on Fraser’s argument above, my reading of the selected narratives seeks to ascertain how cultural artefacts (re)construct bodies of PWA. Indeed, I show that representations in the selected narratives in their various mediums can enforce or disrupt beliefs and stereotypes which disqualify PWA as human agents.

Agency is a key concern of this study. The term is defined variously by different scholars. However, while the current study celebrates albinism as a form of human diversity, it also explores diverse ideas about the notion of agency regarding diversity, recognising that it encourages investigation of complementary issues. For example, in “Agency and culture”, the American cultural psychologist, Carl Ratner, argues that agency can be conceived of from an “individualistic” and/or “cultural” perspective (430). From the individualistic perspective, I have utilised the views posited by Albert Bandura (the Canadian American psychologist) as stated in “Social Cognitive Theory: An Agentic Perspective”. In his study, Bandura regards

agency as one's *mental* or *physical* ability to act upon the "nature and quality of one's life" (1). I also think of agency as essentially a human right (1) often undermined by social structures. This thinking resonates with Ratner's assertion that agency is exercised when a person makes their own personal choices (430). However, Ratner further explains that one's agency "rests on" human interdependence (430), and this assumption thus draws attention to the fact that agency has distinct social properties too. Therefore, I examine how individualistic and socio-cultural perspectives of agency of characters and actual subjects with albinism are represented in the chosen narratives. Significantly, all the texts I read corroborate Ratner's view that a "harmonious social relationship" (430-431) increases the possibility of achieving selfhood and agency, to function agentially. Indeed, the narratives I analyse emphasise the need not only to address subjects but also to re-dress social-cultural dimensions that undermine agency. Such is the case of representations in Esmail's *Living in the Shade*, Kama's "Dare to Dream" and even the two short documentary films, which support the proposition that the creation of a "democratic" public sphere, where individuals are free from various forms of victimization, enables one to exert one's agency (Ratner 431-432; Emirbayer and Mische 962-963). I further use agency to mean the narrative potency to transfigure cultural significations of albinism. Lastly, my conceptualisation of agency and my examination of how each chosen text questions or represents agency of characters/subjects with albinism is founded on the view that personhood is indeed shaped by social interactions (Oyserman and Markus 123).

This thesis argues that agency of characters and subjects with albinism is made manifest when narratives represent them as being able to act socially, operate efficiently, and can be instrumental in countering effect-limiting socio-cultural structures, and/or discourses. For example, In Esmail's *Living in the Shade*, Tatu, a character with albinism, is initially depicted as vulnerable and without the capacity to resist the forces that undermine her. However, with the support of other agents, altruistic figures, who discuss and dismiss the hurtful misconceptions about PWA, she overcomes her victimhood, passivity, and her pitiable state. Eventually, she acts to influence her life positively. I also reason, writers such as Gappah and Magubeni, in their respective texts, harness intertextuality in ways that allow their respective texts to engage with utterances that (de)humanize PWA. Regarding the autobiographical accounts, I contend that the representations in these stories expose how conditions such as social acceptance and a lack thereof impacts the agency of PWA. Social ease, such as that enjoyed by Bongelo, in "I am a Human Being – Flesh and Spirit", enables him to exert agency, while troubled social situations, as in Kama's "Dare to Dream", makes it (im)possible for Kama to exercise agency. Lastly, regarding the filmic texts, I demonstrate that these texts not only expose various social cultural narratives that tend to exclude PWA from humanity and normal

socialisation; they also depict empowering mothering as promoting and securing the self-realisation of children with albinism. Being *YouTube* films, these texts also offer a platform where viewers can comment on these respective films to challenge, criticise, and correct allegations that lead to the social marginalisation of PWA. To borrow Fraser's words, I argue that these films "ha[ve] the potential to draw attention to the materiality of [or experiences of people born different] in unique ways [...]" (75). Imafidon speaks of how media is an "effective tool in promoting an education and enlightenment process that is reconstructive and accurately informative of what has already been known of albinism" (*African Philosophy and the Otherness* 119), and to a great extent, the texts I study configure and reconfigure the agency of, or stereotypes, which undermine PWA in the way that they seem to attempt to create awareness regarding albinism. However, in reading the eight selected texts, I have considered Ato Quayson's ethical call as raised in *Aesthetic Nervousness: Disability and the Crisis of Representation* (2007), namely that critics should consider that in narrating non-normative bodies, authors may imbricate the pre-established materiality or "stable disability 'reality' that lies out there" with aesthetic structures (19). Such thinking, I have established, points out that there are elements of representations which reinvent characters with albinism that actually support the stereotypes which dehumanise subjects with albinism, a case mostly pointed out in the discussions on Mutani's, Gappah's, and Magubeni's works, respectively.

### **1.3 Existing Criticism and Points of Departure**

Many literary critics have explored fictional portrayals of albinism and characters with albinism in Africa. Some existing studies include Charlotte Baker and Patricia Lund's research (Baker 2007, 2008, 2010 and 2011; Baker and Lund 2007 and 2009). Most of Baker's literary criticism focuses on the representations of characters with albinism in Francophone fiction (and some Southern African texts) but her assessments do not extensively explore issues of agency. Specifically, in the regions of my study (East and Southern Africa), the available literary criticisms mainly focus on how albinism is depicted as a cultural precarity (Stobie 2020); how fiction subverts race and sexuality as social constructs regarding homosexual characters and those with albinism; whether fictional depiction of characters with albinism "make[s] one imagine ways in which human time is constructed and perceived" (Ndlovu 2018); how fictional representations of characters with albinism deconstruct normalcy and dynamism in relation to disability (Nyakundi 2019); the impact of fictional representation of subjectivity of characters with albinism (Lipenga and Ngwira 2018); whether fiction educates readers about albinism (Baker and Lund 2017); the manner in which fiction reinvents alterity and otherness of characters with albinism (Tagwirei 2015); and the way fiction's "use of liminal fantasy as a

subversive technique” enables characters with albinism “to interrogate a new space for [themselves, and] to investigate [their] own identity” (Robson 2010). I briefly highlight some of these studies here and return to them (and to additional relevant criticisms from fields such as literary criticism, discussions of disability, and explorations of life narratives) in the forthcoming analytical chapters. Baker and Lund’s study dissects Jenny Robson’s *Because Pula Means Rain* (1998) and Ben Hanson’s *Takadini* (1997); texts “aimed at a young adult readership” to study “how fiction contributes to understandings and raises awareness of the human rights of [PWA] in Africa” (272). The critics “[contend] that fiction [has a role to play in] highlighting the multidimensionality of albinism, and related associations and organisations are beginning to recognize its importance in their advocacy for human rights” (272). Like Baker and Lund’s exploration, Chapter Two of my study explores how the two novellas educate children about albinism and the ethics of care for PWA. In Chapter Four, I develop this concern with the pedagogical value of texts in my examination of the short *YouTube* documentaries and my exploration of how the platform’s comment function enables its viewers to educate themselves regarding albinism, and whether this cultivates valid understanding and social consciousness about PWA.

In “Re-inventing alterity: The Woman and the Albino in *Takadini*’s subtext” (2015), Cuthbeth Tagwirei analyses how “alterity is reworked” in Ben Hanson’s *Takadini* (1997). He maintains that *Takadini* propagates “marginalising discourses” in its representation of characters with albinism, as well as women (1, 19). Although Tagwirei’s and my current study explore a common ground – how cultural narratives marginalise albinism – Tagwirei’s exploration concentrates on a single text, “published in 1997 in a more tolerant era” (Tagwirei 1). In view of this assertion, my research focuses on currently produced texts in different forms and genres, which, I argue, create diversity in the perceptions of albinism in relation to cultural marginalisation of PWA and informs issues of agency as configured variously in cultural and literary texts.

Another important source is Ken Lipenga and Emmanuel Ngwira’s “Black on the Inside: Albino Subjectivity in the African Novel” (2018), which studies “the representation of albinism in four African novels” and discusses how “albinism is presented as a bodily condition that intersects with other experiences on the continent, including indigenous epistemologies, gender, sexuality, and family relationships” (1472). What is vital for my study, is Lipenga and Ngwira’s Disability Studies approach, and their recommendation to broaden research to include other fictions and mediums of representation of subjects and characters with albinism (1485). I aim to address this lacuna (as identified by Lipenga and Ngwira) and to add to existing scholarship

by bringing together texts in various genres and mediums from, and set in, East and Southern African regions.<sup>9</sup> The purpose is to explore how these texts cultivate and recultivate agency of characters and subjects with albinism, through their use of specific narrative modes and methods, including narrative perspective, auto/biographical framing, visual techniques, voice, theme, setting, form, and language use.

However, as indicated above, several literary criticisms on representations of albinism mainly focus on fiction produced by Southern African writers. Fiction is but a segment of the richly growing oeuvre of cultural and literary texts dealing with albinism and PWA produced in the regions I explore. I acknowledge that there are also fiction and life narratives in various forms, media, and platforms by African or Western writers/producers, but these chosen and studied texts testify to some that have been excluded in existing scholarship. Given the word limit of this thesis and time frame, I was compelled to be selective in terms of genres, forms, and mediums this study dissects. Even so, literary critics such as Lipenga and Ngwira acknowledge that “in arguing for the voice of the [PWA]” to “credit” a single medium of expression might “limit[...] opportunities for learning” (1485). Such is the case because each genre, say for example fiction, is limited in its capacity for representation. Thus, the current study entails a purview grounded in a literary and cultural investigation of fictional and non-fictional (written and filmic) texts set in East and Southern Africa; regions where persecution of PWA appear to be notorious, and where literary and cultural texts with an agenda of depicting characters or subjects with albinism in an empowering way, have been on the increase during the past two decades. My study is therefore a multi-disciplinary and cross-cultural reading of the representations of albinism and characters or individuals with albinism as depicted in literary and cultural texts (in written and visual forms), some of which have received little or no critical attention. It contributes to existing criticism of African fiction featuring characters with albinism and expands the available criticisms by including auto/biographical narratives, written and in short documentary form that represent lived experiences of subjects with albinism. Among others, my thesis addresses the following questions: How is the agency of characters and subjects with albinism made manifest in fiction and life narratives from East and Southern Africa? How are the roles and agendas of social institutions and the interpersonal relations of persons with and without albinism represented in the narratives? Do they empower or disempower individuals with albinism according to the way they portray favourable or unfavourable circumstances that promote or hinder affirmation of their agency? Lastly, how do

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<sup>9</sup> I elaborate on my choice of texts and regional focus in the analytical and concluding chapters. In Chapter Five I refer to avenues for further research, and I highlight mediums and forms of representations which remain unexplored.

representations of albinism in these chosen narratives reinforce or challenge cultural truisms about the condition, and how do they advocate a view of albinism as a form of human diversity?

In addressing the above questions, this dissertation presents a literary and cultural analysis of the selected materials by interrogating their formal and thematic aspects. It scrutinises the respective materials' techniques of representation, such as characterisation, depiction of subject(ivity), language use, narrative structure, visual techniques, narrative voice, and themes to establish how the narrative strategies function to reveal and clarify different social cultural aspects and issues related to agency and experiences of characters/subjects with albinism. Therefore, the study contemplates how rhetorical expressions and narrative strategies in each of the selected texts are employed to manifest the individual and social agency of characters or actual subjects with albinism, and how these strategies create awareness of the condition. Furthermore, the analysis considers how the respective characters or subjects with albinism in each of the chosen texts relate to other characters or subjects in the narratives, the different social roles they play, as well as the mediating function of social agencies (such as educational facilities and humanitarian organisations) in their lives. Finally, the question arises of whether narrative perspectives, intertextual insertions, and characterisation or (self)representation, enable readers' recognition of the imagined and lived experiences of PWA, not merely as victims, but as active figures resisting undermining discourse, as autonomous members of society. Thus, I explore how the social conditions of characters and actual subjects with albinism are depicted to address issues of vulnerability, respect, and recognition of PWA as human agents.

#### **1.4 Theory and Chapter Framing**

As noted above, albinism in the texts I have read is narrated as a disability, and as a condition that elicits various forms of distress, ranging from physical assaults and verbal injury to experiences of, for example, loneliness, isolation, discrimination, stigmatisation, and marginalisation. Experiences and conditions related to PWA is also articulated as a state that intersects with various social cultural aspects, such as local superstitions and myths. More so, the studied texts seem to point out various social cultural notions that promote interference with the agency of PWA. All these factors (including the choice of genre) generate various theoretical implications that informed the structure of the thesis. Thus, the chapter divisions have largely considered issues such as genre, thematic focus resulted from different conception of agency, and the theoretical perspective pertinent to the agency and issues discussed in each chapter. Such a division is helpful for my analytical focus and allows ample space for an interrogation of the texts through an engagement that considers the texts' literary forms: fiction

(children's novellas and novels meant for adults) and nonfiction (visual and written auto/biographical narratives). Furthermore, the chapter divisions reflect the analysis which focusses on key thematical issues affecting narrativization of agency as emanating from the respective studied texts. For example, how altruism cultivates agency of children characters with albinism; whether intertexts, deployed in fiction, (dis)allow public agency and appreciation of albinism and characters with albinism; and the manner through which sociality (social relationships, familial, intimacy and friendship, to mention a few) (dis)enables a subject's agency. Thus, while agency is the key denominator binding these chapters, each chapter deals with agency in relation to prominent narrative techniques or motifs deployed and narrated in relation to issues of albinism in the texts studied. So, for example, I concentrate on altruism and personal agency (in Chapter Two); intertextuality and public agency (in Chapter Three); as well as sociality and ontological agency (in Chapter Four). Furthermore, issues of agency (as narrated in the texts I study), genres and the perspectives from which agency is conceived have motivated the chapters' arrangement because each chapter calls for the deployment of specific critical ideas, as briefed in the chapters' layout.

My study is organised into five chapters. Apart from the current introduction, there are four more chapters in this dissertation. Three of these are analytical discussions, beginning with Chapter Two, "Altruism and Agency in Fictional Representation of Children with Albinism". In this chapter, I read two children's novellas, Mutani's *Human Poachers* and Nahda Esmail's *Living in the Shade*, examining how their representational techniques, notably the narrative perspectives, language use, and themes such as vulnerability and altruism limit or allow agency for characters with albinism. I also explore how the said techniques signify vulnerabilities of the respective texts' protagonists with albinism and consider how each of the texts deploys the motif of altruism to combat the injury suffered by their respective protagonists. Regarding these texts, the discussion contemplates how the agency of children with albinism is configured, reconfigured, or undermined through altruistic manoeuvres, and whether such manoeuvres enable each child character with albinism to emerge as an agent of the self and as equal to their dark-pigmented counterparts. I invoke ideas from vulnerability studies, especially Judith Butler's, to elaborate that much as vulnerability can disempower one, it can also be a site of agency. The chapter further draws on critical ideas from disability studies, notably as advanced by Rosemarie Garland-Thomson, Tobin Siebers, and Clare Barker to highlight how social factors disable or enable characters with albinism and to ask whether fictional portrayals of the characters re-assign stereotypes associated with disability to them. Furthermore, I deploy the notion of *Ubuntu* discussed by various African philosophers, including Magobe Ramose and Desmond Tutu, to unfold how altruistic characters (dis)empower those with albinism.

In Chapter Three, “Intertextuality and Agency: Characters with Albinism in Gappah’s and Magubeni’s Novels”, I examine Magubeni’s and Gappah’s novels as meant for adult readership. My interest is in the authors’ deployment of oral and written intertexts to represent agency and experiences of female characters with albinism. I demonstrate that intertextuality in these texts is a representational technique which (re)signals social cultural and historical perspectives defining albinism. I reflect on how these perspectives shape the agency and the life experiences of characters with albinism— the chapter examines agency in the light of the narratives’ capacity to re-signify pre-established beliefs about albinism. It therefore illustrates how these perspectives (re)make demeaning framings of albinism and people with the condition. In view of this, I make use of various theoretical views regarding intertextual insertions in fiction. Key among these is Julia Kristeva’s notion of intertextuality, and her predecessor, Mikhail Bakhtin’s concept of dialogism. I engage these scholars’ ideas: the literary criticism of Isaac Ndlovu, Gibson Ncube and Asante Lucy Mtenje, Lipenga and Ngwira, and the thinking of the Ghanaian critic of disability studies, Ato Quayson, to discuss the ways Gappah’s and Magubeni’s novels (re)articulate social cultural figurations confounding people born different and as PWA.

In Chapter Four, “Sociality and Agency: Narrating Lived Experiences with Albinism in Auto/biographical Narratives”, I first analyse written autobiographical accounts, namely Kama’s “Dare to Dream” and Bongelo’s “I am a Human – Flesh and Spirit” and thereafter interpret the two short documentary texts, which (as explained in section 1.1) have similar titles: *I Will Never Give Up On My Albino Children* / *BORN DIFFERENT*. Since this chapter examines agency in relation to conditions of sociality, I present the idea of agency in relation to (uneasy) sociality as advanced by the feminist critic, Sarah Drews Lucas, who also builds on the ideas of the political philosopher, Hannah Arendt. I thoroughly explore these scholars’ views as they relate to Imafidon’s theorisation on how the African conception of disability (and albinism in particular) might pose existential challenges to PWA and consider their impact on the studied subjects’ personal and public agency. The texts discussed in this chapter are life narratives, and so their respective discussions educe theorisation on how life narratives challenge institutionalised thinking regarding certain subjects. I thus refer to the work of Sidonie Smith and Julia Watson, Susannah B. Mintz and G. Thomas Couser. In the two autobiographical accounts, I examine the way that techniques representing self or subjectivity convey an understanding of lived experiences — of living with albinism. The central focus is on how the lived experiences narrated in the autobiographical narratives speak of agency in relation to social relations. I particularly examine the role of social relations (both intimate and more broadly interpersonal) and lack thereof. Subjects have to endure or negotiate loneliness, discrimination and isolation, to mention only a few indignities. Also, granting or limiting public

or private agency of subjects with albinism needs to be taken into consideration. Lastly, in reading the two documentaries, I focus on representational techniques, such as a selection of shots and particularly the voice of the respective translating narrators/interviewers, and how these elements bring to light issues of agency. I consider whether these filmic representations expose, challenge, or reinforce social structures that induce social exclusion of PWA and their relational others, issues which also impact on their agency. To analyse these films, I echo the assertion that African film makers use a “camera as a tool to counter the [...dominant and undermining] representations” of Africans (Ellerson, “African” 1). Furthermore, the *YouTube* comments function as “heterotopias” defined as “spaces that is capable of affording alternative, dominant discourses which, according to Grant Andrews, “potential[ly...] disrupt offline spaces[’]” (87). I argue that the first-person “I” in autobiographical texts effectively allow PWA to represent themselves as human first, compared to the third-person narrations sometimes favoured by the translating narrators in the films.

Finally, Chapter Five, which is the concluding chapter of this study, summarises my findings. It also reflects on the degree to which the different narrative forms, genres, and mediums I have studied employ diverse strategies in representing characters and subjects with albinism, to undermine or to cultivate their agency. The chapter further discusses problems encountered in undertaking this study and elaborates on genres and modes of representation that can be useful for my own and other interested scholars’ future research.

## CHAPTER TWO

### ALTRUISM AND AGENCY IN FICTIONAL REPRESENTATION OF CHILDREN WITH ALBINISM

#### 2.1 Introduction

In the general introduction of this thesis, I explained: my study aims to examine how authors/producers configure and reconfigure agencies of characters or subjects with albinism in narratives. It is therefore important to note that agency, one's capacity to make things happen in one's life, varies depending on social, cultural, and economic structures as well as the kind of circumstances one has to live through. Some individuals, such as privileged adults with albinism, can maintain a relatively high level of freedom and even have voice in their lives. In his study on agency, "Toward a Psychology of Human Agency", Bandura opines, individuals are deemed to exercise agency when they exhibit that they are "contributors to their life circumstances, not just products of [those circumstances]" (164). The implied idea here is that individuals with this capacity (agency) can stand as agents of the self and enhance their lives. However, there are individuals who are incapable of acting on their own behalf because their life circumstances may undermine their agency. They consequently need people who can act on their behalf. For example, when children are disregarded by their society and people who should have cared for them, they are, as Albert Bandura reminds us, without "direct control over conditions that affect their lives", hence, they need to "exercise socially mediated agency, or proxy agency" ("Toward a Psychology" 165). With this kind of agency, an individual or something in their situation may influence "others who have the resources, knowledge, and means to act on their behalf to secure the outcome for them" (Bandura, "Toward a Psychology" 165). The support of altruistic individuals is one of the ways whereby such agency can be brought about.

Given this understanding, this chapter examines how and whether altruism, the concern for the welfare of others, impacts the personal agency of child characters (with albinism), focusing on two children's novels set in Tanzania: Elias Mutani's *Human Poachers* (2016) and Nahida Esmail's *Living in the Shade* (2011). Mutani and Esmail are Tanzanian writers. Mutani's novella, *Human Poachers* tells the story of Jasiri, a boy with albinism who is hunted by people, human poachers, who want his body parts, while Joan, a child without albinism, offers to help him. Likewise, *Living in the Shade* by Esmail relates the story of Tatu, a girl with albinism who is excluded from her school community and society at large. Like Jasiri, Tatu is hunted for her body parts by Juma and his friend. Jasiri's and Tatu's circumstances change because of other

characters' kind-hearted actions, such as Joan's (*Human Poachers*), Brother Karimu's and Sister Julianne's (*Living in the Shade*).

It is important to note that both *Living in the Shade* and *Human Poachers* won the Burt Award for Tanzanian Young Adult Literature<sup>10</sup> in 2011 and 2016, respectively. Mutani is the author of two fictional texts for children: *Human Poachers* and *The Wanderer and the Golden Paper Knife* (2019). He works as a writing coach to youth and emerging writers, as psychotherapist and as a scout master (Kuria 24). Esmail is a prolific, multi-award-winning<sup>11</sup> author whose oeuvre includes many independently and co-authored storybooks and educational texts for children and youths, such as: *Mahmood My Hero* (2008), *Living in the Shade* (2011), *Lessilie - the City Maasai* (2012), *The Detectives of Shangani: The Mystery of the Lost Rubies* (2014), *Living in the Shade: Aiming for the Summit* (2017), *Karafu: A Freed Slave* (2017) and *What is Islam?* (2017).

I comment on *Living in the Shade* and *Human Poachers* as children's literature based on Barbara Wall's clarification in her book *The Narrator's Voice: The Dilemma of Children's Fiction* (1991). According to Wall, children's literature entails a "body of [narratives] written specifically for children" and young adults (1). For Wall a child is a person aged less than 13 years and a young adult is one aged below 18 years (Wall 1). However, this classification is contestable because societies may differ on when one ceases to be a child or interested in reading children's texts. Nevertheless, Esmail's and Mutani's texts are specifically intended and marketed for pupils and students in Tanzania. The books were produced under the Children's Book Project for Tanzania (CBP), a non-governmental organisation which aims at "developing a strong reading culture and societal appreciation and support for literacy" (Esmail "Acknowledgements and Foreword" iii-iv). Moreover, these texts are deemed children's literature because they exhibit representational techniques, such as structural arrangements, language, themes, and illustrations that are simple enough to accommodate the child reader. However, it is understood that literary readership is flexible, and children's literature represents assumptions of "adults' attitudes towards children" because most authors of children's literature are adults who use "text[s] and illustration[s]" to "instruct, and [...] comfort or entertain" children (Dennis, n.p). Here again, in making these texts part of my inquiry, I consider their

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<sup>10</sup> The Burt Award is "sponsored by Canadian Philanthropist Bill Burt, is part of ongoing literacy programs of the Children's Book Projects for Tanzania and CODE, a Canadian NGO supporting development through Education" (Mutani Acknowledgement iii)

<sup>11</sup> According to the Burt Award website, "<https://www.burtaward.org/nahida-esmail>", Esmail is an award-winning author of four young adult novels and ten children's picture books, three of which have been translated into Swahili and one translated into Maa, the language of the Maasai. Esmail received The African Young Adult Literary Award in 2014, 2016 and 2017.

educational and moral value and how they communicate the personhood of children with albinism to the (child) reader.

Although there are several other children's texts,<sup>12</sup> particularly set in East Africa and Tanzania, which feature children with albinism as main characters or albinism as their main theme, I chose Mutani's and Esmail's texts because of their educational significance, since they are primarily meant to support children's literacy.<sup>13</sup> More so, these texts have similar properties in their modes of representation, which seem to deploy the theme of philanthropism (individual and collective support) in their discussion of the agency and wellbeing of children with albinism. Furthermore, to my knowledge, these texts have received no scholarly attention — a telling omission, considering their portrayal of persons with albinism.

In reading these texts, I examine how each author of these respective novellas develops the motifs of philanthropic or benevolent figures to represent individual and social altruistic efforts to help children with albinism to gain agency. I further consider how and whether each of the narratives' representation of altruistic efforts proves that well-meant intervention successfully provides protection and empowerment that must enable the respective characters with albinism to achieve agency. Furthermore, the chapter establishes whether each writer's representation of altruistic figures and a character with albinism constructs or criticises stereotypes that negatively frame children with albinism and albinism as a condition. The chapter's argument is that in the narratives studied, philanthropism is represented as a necessary intervention to protect, empower, stimulate and/or afford agency to child characters with albinism. However, there are moments of representation where altruistic efforts by characters without albinism signal discourses of protection which bear ambivalent meanings for the agency, empowerment, and personhood of characters with albinism. Such discourses are evident, for example, in

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<sup>12</sup> For example: Tara Sullivan's *Golden Boy* (2003) and Nahidi Ismail's *Living in the Shade: Aiming for the Summit* (2011), a sequel of *Living in the Shade*.

<sup>13</sup> These books are among the texts that CODE distribute to secondary and primary schools where they are used as supplementary readings. Both Mutani's and Esmail's books contain glossaries. Mutani's has a glossary which explains Swahili words in English and Esmail's contains a list of English words with definitions which is aimed at developing the second-language English speaker's vocabulary. In line with this educational agenda, The Burt Award website (<https://www.burtaward.org/nahida-esmail>) also clarifies that Esmail's novella was "honoured with the Tanzania Women's Achievement Award in the education category" in 2015.

I understand, in being sponsored by a non-governmental organisation with specific educational agendas, Mutani and Esmail respectively might have been compelled to make certain thematic and rhetorical choices. Their respective stories might have been influenced by their initial understanding of the topic of albinism and by sponsorship agendas too. Each writer probably negotiated a balance between the sponsor's expectations and their individual creative intentions. That said, sponsorship thus can be problematic if the author's intentional rhetorical choices and thematic aims do not fully resonate with the sponsor's agenda. Yet, given the misconceptions of albinism and maltreatment of people with albinism, sponsorship nevertheless affords cultural practitioners an opportunity to contribute to a global, ethical concern – the marginalisation of individuals regarded as 'other'. While sponsorship then plays a significant role, in my view, each selected text should be evaluated for its unique literary qualities and valuable ethical contribution to albinism discourses.

Mutani's troubling representation of Jasiri, the child with albinism, whose story is juxtaposed with Joan's, another child (without albinism), who acts as Jasiri's protector of sorts. I argue that, although the character (without albinism) is meant to highlight kindness to those with albinism who need help, the generosity disregards the agency of the protected character. This however contrasts with Esmail's text in which altruistic characters seem to reinforce Tatu's ability to act as an agent of the self.

### **2.1.1 The Chapter's Contribution, Point of Departure and Theoretical Ideas**

Focussing on *Human Poachers* and *Living in the Shade*, children's novellas that have remained relatively unknown and under-examined, this chapter contributes to the body of literary criticism that studies agency of characters with albinism in fiction from Southern and East Africa. While the chapter acknowledges that there are several studies that consider agency of characters with albinism in fiction, it also recognises that the available studies neglect the relationship between altruism and agency as their critical focus of inquiry. To address this lacuna, the current chapter assesses how and whether individual or social, collective efforts, as represented in the altruistic actions of characters deemed normal, affect agential traits of child characters with albinism.

Theoretically, because Mutani's and Esmail's narratives respectively construct albinism as a form of vulnerability and characters with albinism as vulnerable figures, the discussion draws on ideas from vulnerability and disability studies, proposed by scholars such as Judith Butler, Rosemarie Garland-Thomson, Tobin Siebers and Clare Barker. In discussing altruism from an Afrocentric perspective, the chapter engages ideas concerning the notion of "*ubuntu*" (discussed below). Further, it draws on various voices from African critics of children's literature to interpret the didacticism of these texts intended for young children. Thus, to examine how characters with albinism are imagined as vulnerable and whether vulnerability affects their agency, necessitating the need for altruism to ameliorate their vulnerability, I turn to Judith Butler, Zeynep Gambetti and Leticia Sabsay's ideas on vulnerability and vulnerable subjects. According to Butler et al. in *Vulnerability in Resistance* (2016), vulnerable subjects are always conceived as lacking agency and are framed as though "[they are in] need for protection or, indeed, philanthropy" (Butler et al., Introduction 9). Such framing, Butler et al. say, in the introductory chapter of *Vulnerability in Resistance*, equates vulnerability with "victimization and passivity" and suggests vulnerable figures as "invariably the site of inaction" (1) which is arguably not always the case. As I read the narrative framing of child characters with albinism being helped by those without, I remain cognisant of the supposition of Butler et al. that "vulnerability [can also be] imagined as one of the conditions of the very possibility of

resistance” (Introduction 1). With that thinking, I consider whether each text studied here reinforces the “[contested] idea” that a vulnerable figure is incapable of acting for themselves and whether they always need paternalistic intervention, which is understood to be “the site of agency” (Butler et al., Introduction 1). Henceforth, I read the two novellas as presupposing that, although children with albinism are individuals “who understand themselves to be in precarious positions”, they can still “enact a form of resistance” which signals their realisation as agents of the selves who seek to contain their vulnerability (Butler, “Rethinking Vulnerability” 15).

Additionally, in discussing how social and material disablement affect the agency of characters with albinism, the chapter refers to Rosemarie Garland-Thomson’s notion of the “Misfit” as explained in her article: “Misfits: A Feminist Materialist Disability Concept.” Garland-Thomson, who is herself a disabled person and a thinker on the justice of disability, developed the notion of the “misfit” to describe the incongruent relationship between one’s body and one’s surroundings, which might exclude one from being part of a community, thereby affecting one’s agency (“Misfits” 592-593). I use “misfit” to examine how the vulnerability of child characters with albinism is heightened because they are “rejected by others for [their] conspicuously odd, unusual appearance” (Garland-Thomson, “Misfits” 564). I consequently demonstrate how this state of “misfitting”, which is intensified by the lack of “a material context of received and built things ranging from accessibly designed built public spaces, welcoming natural surroundings, [...] tools, and implements, as well as [accommodative] people” (“Misfits” 564), is represented as affecting the agency of child characters with albinism. Furthermore, I cite “misfit” to ascertain whether and how the texts studied deploy altruism to signify that an inclusive society may enable children with albinism, previously framed as misfits, to fit in and to exercise their respective agencies. I explicate this point as I trace the motif of the charitable organisation in Esmail’s *Living in the Shade* to establish how altruistic characters’ moral support and their advocacy for inclusive society enables Tatu’s agency.

Given that people or characters with albinism are disabled and degraded by social factors, as reflected in the texts under study, my analysis of whether the child character with albinism is imagined as such or transcends such framings invokes Tobin Siebers’ notion of “the ideology of ability”, the notion he eloquently explicates in his work: *Disability Theory* (2008). According to Siebers, “the ideology of ability” entails the social cultural “preference for able-bodiedness [...as] the baseline by which humanness is determined, setting the measure of body and mind that gives or denies human status to individual persons” (8). In the narratives I study, child characters with albinism are described as ghosts and *zeruzeru* — nothing, terms that imply them to be incorporeal and lacking agency. Therefore, I deploy Siebers’ ideas to discover how the

portrayals of children with albinism in the narratives studied endorse or resist the ideology of ability — the social framing of albinism as the marker of a body deemed debilitated, unproductive, ineffective, and extremely vulnerable and therefore inhibiting those living with albinism from being agents in their lives.

Complementing Siebers' arguments is Clare Barker's ideas on how children with bodily deviances are set up as tropes of representation in postcolonial fiction. In her elaborate work: *Postcolonial Fiction and Disability: Exceptional Children, Metaphor and Materiality* (2011), Barker stipulates that, given philanthropic interventions, which are often regarded as perverse in the postcolonial world, narrative representations of children deemed deviant are always exaggerated to provoke "generous contributions from the public in times of need" (12). However, such depictions, Barker reminds, may serve as the "powerful, universalizing symbolic order that effectively obscures the specificity of disabled children's experiences, denies their agency, and obstructs the [audiences'] engagement with the historical and cultural events that produce and perpetuate global disability" (12). With Barker's ideas in mind, my discussion enquires whether Mutani's and Esmail's respective representations of altruistic ideas depict children with albinism in a fashion which undermines their agency. Furthermore, in considering Barker's insights, I examine whether each narrative's altruistic agenda responds to the representational trope that takes human deviance, in this case albinism, as the marker of victimhood and helplessness — stereotypes that may deny a character full humanity.

In addition, my discussion engages Vivian Yenika-Agbow's ideas on representations of children as considered in her book: *Representing Africa in Children's Literature: Old and New Ways of Seeing* (2008). I particularly draw on her observation regarding the portrayal of children in children's texts written for children "through material and symbolic forms" (xv). Her very fascinating argument is that, regardless of whether imaginings of children in children's narratives are accurate or not, when they are internalised by child readers, they may serve as "the sole means through" which child readers "interpret[...]" perplexing phenomena (Yenika-Agbow, *Representing* xv) like albinism in their real life. Yenika-Agbow's ideas are useful for my comment on whether written representations in the examined texts "question/challenge inappropriate images" (*Representing* xvi), and the stereotypes associated with albinism.

Lastly, I evoke the notion of *ubuntu* to enrich the discussion on the motif of altruism from an Afrocentric view. The term *ubuntu* is regarded in different ways by several scholars, but the work of Nobel Peace Prize winner Desmond Tutu — *No Future Without Forgiveness* (1999) primes my inquiry. Tutu conceives *ubuntu* as an African view of life in which one must be "generous, [...] hospitable, [...] friendly", "caring and compassionate" towards others for the

sake of a harmonious society in which people, irrespective of their differences, flourish together (31). However, *ubuntu* is a debatable notion, so I further engage with several critics' ideas in exploring altruism. One among these is Mabogo P. More, whose study, "Philosophy in South Africa under and After Apartheid", defines *ubuntu* as a "relationality" that does allow a good ground for human well-being because it provides interdependence, communal support, communal networking and communal security that is needed for other people to thrive ("Philosophy" 156). I also remain cognisant of slight differences in the understanding of *ubuntu* across critical perspectives. As for example, in some versions of *ubuntu*, one's gender (e.g., femininity) and bodily difference may "exclude [one] from *ubuntu*'s humanness from the moment" they are born (Seehawer 456). Tutu's version of *ubuntu* is suitable for my study for it echoes the African philosophical conception of life and respect of humanity for the greater good. The very things the texts I study seem to advance. Thus, in reading the texts, I reflect on whether altruism in the narratives inquired bears representations which "[promote...] cultural tolerance and appreciation of [human differences]" (Letseka "In Defence" (56), including albinism. As I argue, although altruistic characters are intermediate agents who (in Mutani's text) serve the character with albinism, it is also a technique through which the body of a character with albinism is problematically exposed as weak, passive, and overly dependent on bodies deemed normal. In Esmail's text, altruism is clearly emanating as an empowering device, which not only ensures her protagonist's survival, as in Mutani's story, but also creates an environment where a character with albinism stands as an agent of the self.

My literary interpretation draws attention to the authors' use of specific rhetorical strategies which function to foreground issues of altruism, vulnerability, and agency, such as narrative perspective, characterisation, metaphor, diction, or tone, and I examine particularly themes of (self)protection or, what I term 'saving the self or being saved', as advanced by the motif of charity. In the next sections, I introduce Mutani's *Human Poacher* and analyse how the narrator introduces the personalities of the vulnerable child with albinism, Jasiri, and his proxy agent and protector, Joan. I argue that, through characterisation, Mutani prefigures Jasiri's body as passive and Joan's as energetic and capable of defending the former. Then, the discussion establishes whether and how altruism, which is signified in the author's depiction of Joan as protector of Jasiri, effects agency of the latter. My position is that Mutani's discourse of protection is ambivalent. Although it takes a moral stance that encourages the protection of an individual with albinism, it also perpetuates and seems to corroborate the point that, unlike other children, children with albinism are excessively vulnerable and that they need safeguarding. They are incapable of being agents of themselves. Furthermore, such a discourse

implies that the protector is also a perpetrator, as someone ignoring or unable to recognise the agency of the protected. Thereafter, the focus of my analysis turns to Esmail's *Living in the Shade*. My interpretation of the text seeks to establish how and whether Esmail's use of the first-person narration mode, the diction, imagery and characterisation, combine to illuminate issues of the agency of her protagonist. I determine how these literary devices provide Tatu, Esmail's child protagonist, with a means of voicing her feelings of being overwhelmed by the conditions of her vulnerability, and hence her appeals for collective social support. I further discuss Esmail's representation of charity as related to a non-governmental organisation's agenda and individual aid, devised to intervene in Tatu's defence. I posit that Esmail's depiction of altruistic efforts signals a technique in which she implies that social and collective agencies can be useful to ameliorate the pressures on people with albinism. In her novella, the NGO and individual altruistic acts are described as acts that accord Tatu a sense of agency, thereby revitalising her to fight for her own recognition and eventually become an agent of the self.

## **2.2 Altruism and Agency of the Protected: Saving and Being Saved in Mutani's *Human Poachers***

While all human beings are vulnerable, Butler et al. remind us that vulnerability is produced and is "unequally distributed through and by differential operation of power" (5). This assertion may imply that age, health, and physical condition, for example, may contribute to one's uneven level of exposure to injury. Likewise, the basic inequalities that one must confront, play a role in one's ability to resist your vulnerability. Such thinking accepts that individuals of the same age, say children, given certain circumstances, may have different levels of vulnerability. As cited earlier, Butler et al. argue that vulnerable people are always framed as powerless, incapable of acting for themselves, and are frequently counselled via readymade humanitarian interventions. Some of these interventions may empower such individuals while others, echoing Butler et al. again, may ignore the fact that even vulnerable figures have agency (6). However, when the agency of those protected is ignored, the very attempts to offer protection constructs the protected population as extremely vulnerable and passive recipients of protection. The protectors, on the other hand, are presented as being invulnerable, agentic, and capable of empowering the vulnerable (Butler et al. 5). These introductory comments serve to highlight how literary texts, particularly those that portray the lives of characters with albinism, might present such a discourse of protection, the concern of this sub-section. My discussion focuses on the recurrent and indeed persistent discourse of saving and protecting children with albinism as foregrounded in Mutani's *Human Poachers*. However, before I explicate such discourse, I

first investigate the ways in which Mutani imagines the vulnerable body versus bodies designated as agentic and therefore capable of protecting the vulnerable.

Mutani's *Human Poachers* centres on two youngsters: Joan, and Jasiri, a boy with albinism, who live in Saanane village. These protagonists' experiences are narrated in relation to other characters such as Jasiri's mother (Berita), Joan's scout squad members (Salu, Egna, and Mpuya), her Scout Master (Master Lwanga), Teacher Clemence (TC) and the Head-Teacher. The story presents Jasiri as a vulnerable child who lives with his mother Berita in Saanane village, the village in which the (unnamed) chairman offers no protection to Jasiri when he is being hunted by the so-called "Human Poachers". The narrative thus centres on Joan, a town-born girl, who visits her uncle in Saanane village and who attempts to outsmart the human poachers who, as she learns, want to kill Jasiri and, according to rumours recalled in the story, have already killed another boy with albinism for his body parts. Therefore, the title *Human Poachers*, lauded as an "attention catching sinister title",<sup>14</sup> signals the danger surrounding Tanzanian children with albinism and encourages awareness of the urgent need to protect or save these endangered children — the central concern of the novella. Mutani's novella can thus be appreciated as one that unfolds a common experience endured by people with albinism. As an African text, Mutani's narrative "is given" its "impetus, shape, direction and even area of concern by social, political and economic forces" which define experiences of children with albinism in Tanzania (Wa Thiong'o, *Homecoming* xv). Creatively, the novella reflects pervasive superstitions, persecutions, and mutilations of persons with albinism in Africa, and evokes the role of the African novel to "[...give a] view of society from its contemplation of social life, reflecting it, mirror-like, but also reflecting upon it, simultaneously" (Wa Thiong'o *Globalectics* 16), while offering forms of advocacy. Citing Tutu, I would say the novella "speaks about compassion" as the means to preserve the wellbeing of children with albinism, because its narration may sensitise child readers to the plight of those rendered vulnerable and the needy (31), encouraging them to offer succour and care.

As I pointed out earlier, I briefly comment on how Mutani characterises his two protagonists, Joan and Jasiri. During my analysis, I demonstrate that Mutani's characterisation signals Jasiri's body as a non-normative one and depicts Joan's as agentic, enterprising, and therefore capable of acting on behalf of Jasiri. Such commentary forms the background for my discussion of discourses of protection and rescue, as well as my examination of what I term *the ideology of scouting* in Mutani's narrative. I argue that in Mutani's novella, the motif of vulnerability occurs simultaneously with the motifs of saving and protection. As we shall see, Mutani imagines Jasiri

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<sup>14</sup> <https://web.facebook.com/pg/mutanielias/posts/>

as extremely vulnerable, being hunted for his life. He also conceives this character as lacking the capacity to safeguard his vulnerability; this renders him unusually dependent on Joan, a character without albinism. Joan then by proxy becomes an intermediary for Jasiri's safety and survival. Despite Mutani's depiction of the two children as being of the same age, he imagines (seemingly purposely) their power and their responses to vulnerability differently. Such a representation (I demonstrate) seems to "establish the disenfranchised as 'vulnerable populations'" and therefore distanced "from prevailing ideas of agency and mastery" (Butler et al. 3-4). This interpretation further manifests as I trace discourses of protection and saving in *Human Poachers* to demonstrate the ways such discourses ascribe a superior position to Joan, while framing Jasiri as the passive recipient of protection. The coexistence of Jasiri and Joan where the latter protects and saves the former works as a technique in which the text denigrates the figure with albinism, denying him enterprising agential traits with an intention to project him as pitiable.

As per Barker's argument, representations of vulnerable children in postcolonial fiction relies on the technique in which "the story of 'the child' has to be made exceptional to achieve maximum impact" so that the figure depicted attracts humanitarian support (Barker 12). In creating the narrative condition that Jasiri needs to be saved by Joan, Mutani invests in the skewed characterisation that exploits human deviance "to carefully manipulate the affective responses of their specific target audiences: appealing to impulses of human empathy and philanthropy" (Barker 12). This technique not only frames Jasiri as the figure in need of rescue, but also "invent[s] realities for how a [child with albinism can be] defined by children readers" (Yenika-Agbow, *Representing* 03) as non-normative. The reader, I will show, is likely to see how Mutani labels Jasiri as lacking the agential traits which would allow him to act on his own behalf; the opposite is true of Joan, his counterpart. I demonstrate how the depiction discloses the ways in which the bodies and inner traits of the two child characters, Joan and Jasiri, are narrated.

As Mutani's narrative begins, the omniscient third-person narrator introduces the reader to the young Joan, whose "heart pounded loudly in her chest" because "[t]he overwhelming news she carried weighed her down. She wanted to pour it out. She could not slow her rapid breathing. Never had she been this worried before" (1). Then the narrator reveals that Joan's "thoughts were on poor Jasiri" and she had "spent the day trying to get some time to talk to [Jasiri alone about her fear]" (1). Suspicion is created as to what has happened to Jasiri and why Joan is the speaker here? Focalisation on Joan then becomes the technique Mutani uses to place "the point of view in or with a specific agent" to subjectify the narrative's acts (Bal 66). One could reflect

on the agential impact of such subjectivation. Granted, readers learn that neither Joan nor Jasiri tells the story, and so the third-person narrative perspective undermines both characters narrative agency, their capacity to directly talk with an ‘I’ perspective about themselves to the readers. However, Joan is foregrounded in the narration of her emotions and experiences. The use of such a technique, to cite the literary critic, Lura Vinas Valley, informs the reader’s “opinion of the story and, therefore, what the readers get is a story filtered through [the narrator’s]” choice, and which particularises how these characters are to be perceived by an audience (294). So, for example, the omniscient narrator singles out Joan as a conduit through which Jasiri’s experiences can be understood. She is thus the singled-out agent by proxy to communicate with the reader because one experiences Jasiri’s story through her interiority. Furthermore, the fact that Joan is immediately introduced as an intermediary agent, who thinks and is troubled on behalf of Jasiri, evokes an aphorism of *ubuntu* as proposed by Mogobe Ramose in “Globalization and Ubuntu”: that “to be human is to affirm one’s humanity by recognizing the humanity of others” (753). This maxim is reflected in the narrative perspective and contributes to Joan’s respect for and recognition of Jasiri’s humanity; she cares for others’ wellbeing.

While the reader still thinks of the relationship between Joan and Jasiri in this skewed manner, the omniscient narrator, who, to borrow Valle’s words, “never stays neutral” (294), introduces the two children by comparing their physical and social traits in terms reminiscent of ideas of “who the ‘good’ and ‘bad’ characters are” in the story recounted (Valle 294). Whereas Joan is described as exercising her social agency: she “has many friends”, “good looks and [her] sweet, friendly voice hooked girls and boys” (2), Jasiri is described as “different from them all” and “unique” (2). This framing is complemented by the comment that he has chosen “to be no one’s friend” (2). This kind of exercise of agency denigrates one’s personhood, because as John S Mbiti, an African philosopher and religious thinker claims (in *African Religions and Philosophies* (1990)), regarding an African conception of a person, one “does not and cannot exist alone except [communally]. He owes this existence to other people,” and “the individual depends on the corporate group” for “whatever happens to the individual happens to the whole group” (106). Being without a “friend” frames Jasiri as an incomplete person, in contrast to Joan, who exists among peers.

Furthermore, in terms of physicality and ability, the narrator reveals that “Joan [is] gifted and loved by her peers”; she plays netball and is of “tall height and lean figure. When she stretched her legs and hands, she scored big numbers” (2-3). This able-bodied physique is emphasised in an illustration of Joan (see figure 2), featuring her in her scout’s uniform.



**Figure 1: Joan in her scout outfit**

The illustration and the rhetoric in the quotations project Joan as having socially and bodily likeable qualities, characteristics Jasiri apparently lacks. The narrator comments: Jasiri “was popular at school due to the colour of his skin, eyes and hair” and therefore defined as “no other than Jasiri” (2). He thus was known primarily for his albinism. While Mutani’s reliance on clinical manifestations of albinism, to characterise Jasiri, echoes the social reality where a PWA is understood solely in terms of their skin, colour, hair, and eyes, such characterisation might eschew “the universal experience of [being a child with albinism]” (Yenika-Agbow, *Representing* 12), and may infer albinism as the marker of reduced bodily and social capacity. As I said, it seems that Mutani characterises Jasiri as someone with a muted inner and external personality to create an image of a needy child. Images of that kind might evoke pity and/or provoke “generous contributions from the public” (Barker 12). With this portrayal, the narrative may imply that Jasiri might depend on Joan’s enterprising body for his survival. One may then suggest that Mutani extends Joan’s inner and external personality to frame her as the main protagonist, a method that further mutes Jasiri’s inner personality or agency.

However, it should be noted that even when later narrative moments attempt to balance Joan’s and Jasiri’s athletic abilities (Jasiri is commended as being good at football), such moments are still marred by the narrators’ rather questionable decision to remind the reader of Jasiri’s “wobbly eyes”, “pinkish skin”, and “white hair” (44). Such sustained descriptions of Jasiri presuppose a stereotype, that one’s impairments make them “a null set” (Quayson, *Aesthetic*

*Nervousness* 52); a stereotype in which the personality of a disabled subject is reduced to mean they are nothing (*zeruzeru*), even when Mutani attempts to refute the myth that “albinos” are ghosts (126) – a myth that renders people with albinism as disembodied, hence without efficacy.

Therefore, in presenting these characters in these ways from the outset, Mutani’s choice of narrative perspective appears to agree with what Mieke Bal postulates as a method by which authors mould their characters: assign them with unlike roles and traits to make certain “ideological descriptions possible” (105). As noted, the ideology that informs the narrator’s characterisation of the two children is bias. Whereas Joan appears strong, heroic, and complex, as reflected in the motif of philanthropy, Jasiri is timid. Here, the narrator could be hinting that Joan should utilise her resourceful body to ‘rescue’ Jasiri. This point signals a possible misconception, especially in the light of Joan’s portrayal as resourceful and agentive, and thus able to act on behalf of Jasiri, who by comparison does not have the capacity to act in his own behalf and thus appears to be lacking in agency. As the narrative advances, that which I termed Mutani’s altruistic agenda comes to define Jasiri and Joan’s relationship, in which the former is projected as more enterprising than the latter. This depiction began to unfold when Joan arrived in Saanane village, where she founded a scout squad. On one of her scout missions in the forest, Joan overhears a conversation between two unnamed male abductors (the titular ‘poachers’), plotting to abduct a boy from the village in the belief that, “the boy’s body [...will] fetch them money” (8). These poachers are ready to kill the boy’s mother if she interferes in their plan. They say: “she will bathe in her own blood” (8). From the poachers’ conversation, Joan guesses that the targeted boy might be Jasiri, who lives with his mother, seemingly abandoned by the father. This narrative event presupposes the “‘rhetoric of the sentimental’” where the representation of a vulnerable figure “‘produces the sympathetic victim or helpless sufferer needing protection or succor and invoking pity, inspiration, and frequent contribution’” (Garland-Thomson as quoted in Barker 12-13). Concern for Jasiri and Berita’s lives is aroused when it is clear that the human poachers see them as worthless. My interpretation then is that Joan’s fears for Jasiri’s safety, noted earlier, signify her initial altruism; she cares about Jasiri’s wellbeing, and that projection recalls Ramose’s explanation that so long as one is “a-living-human” he/she “deserves recognition by all other human beings”, and “this recognition must be understood to mean both respect for and protection” of his/her humanity and life (“Globalisation” 732). Indeed, Joan is worried that the poachers will kill Jasiri and Berita, who are rendered victims — seemingly helpless. The depiction may evoke the child reader to consider children with albinism as per *ubuntu* maxims: to treat the needy with “dignity” and “respect” (Mokgoro 17) and where necessary to act for “a greater humanity”; humanity “that

transcends alterity of any form” (Swanson 55). This evocation manifests in the narrative where Joan serves as an intermediary agent who must act on Jasiri’s behalf.

So, Joan reminds us of the urgent needed to save Jasiri from the pending planned ‘poaching’ via her insistent urgent need to talk to him, a moment the narrator describes as Joan’s “golden chance” (2), the narrator’s way of signifying that Joan’s intervention is the only way to save Jasiri from the arranged murder. One then expects that Joan might treat Jasiri exceptionally considerately. Indeed, in “Anchoring Ubuntu Morality” Letseka mentions the qualities of “young people who are initiated into *Ubuntu* morality” (351). Among, others, Letseka is of the view that young people with *ubuntu* virtues are “inclined to [treat] others with fairness at all times” (“Anchoring” 351). Such an observation resonates Ramose’s assertion that a person with *ubuntu* spirit has the capacity to “recogni[se] the humanity of others” because an *ubuntu* centred ethic requires one to “establish humane respectful relations” with other individuals (“Globalisation” 753). However, contrary to readers’ expectations of seeing Joan as having a caring nature, one is surprised when Joan meets Jasiri and treats him quite harshly. The narrator states:

Jasiri [...] *sensed the danger* behind him. He started to run but Joan was faster. Her tiny hands *grabbed his shirt and pulled him to the ground*. Jasiri was finally lying sprawling on the ground [...] He stood and ran away from Joan. “Stop!” Joan ordered. [...] Jasiri was not listening. [Eventually, Joan] jumped forward, stretching her right foot as her toes *curled on his foot*. The boy’s legs became interlocked. *He fell with a loud thud crying in pain*. (2, my emphasis)

The emphasised phrases might well raise doubts about Joan. Is she truly compassionate or does she have a hidden motive? Joan is depicted as physically rough in the imposition of her will on Jasiri, who chooses not to listen to her call. Given the good intention that Joan supposedly has concerning Jasiri’s life, the scene suggests that violent intervention in the lives of people with albinism is called for, in the service of greater good. It also implies, Joan acts the way she does for the sake of making Jasiri understand that she is under pressure to save him from the impending kidnapping and murder. Even so, the image of the pitiful Jasiri subjected to Joan’s violence, however, is distorted in Mutani’s subsequent attempts to depict Joan’s true motive, which initially seemed so violent. After the drama, Joan eventually tells Jasiri: “I want to save your life. Bad people are after you. Don’t sleep at your house tonight. It is too dangerous” (10). This narrative shift frames Joan as Jasiri’s intermediary agent who challenges the norm that excludes Jasiri and, by implication, other children with albinism, from the world; where their “lives are not ‘regarded’ as potentially grievable, and hence valuable”; the world in which they

“are made to bear the burden of [...] differential exposure to violence and death” (Butler, *Precarious Life* 25). Put against her former harsh acts, Joan’s altruistic intention (her desire to save Jasiri) signals how “humanitarian [...] practices that are designated” for figures “in need of protection” not only “negate [the agency] of those declared vulnerable to act politically, but also expand [...] forms of regulation and control” (Butler et al., 5). As such, those who act on behalf of others achieve some form of control. Since *ubuntu* insists on courtesy and good will, Joan’s coercive treatment of Jasiri renders Mutani’s depiction of altruism problematic. Thaddeus Metz speaks about acts which embed *ubuntu* qualities that are expected of a young African. In his work: “Towards an African moral theory”, Metz avers, any act said to have *ubuntu* virtues must “reduce [...] discord” and “produce harmony” regarding “a matter of identity and solidarity” (“Towards” 340). The point Metz raises here is that a person with *ubuntu* must demonstrate respect to others irrespective of who they are, the very quality that Mutani’s concept of altruism, as depicted via Joan’s relationship with Jasiri, is deemed to be lacking.

Furthermore, in *Human Poachers*, hegemony is also noted in the depiction that contrasts Joan’s and Jasiri’s reaction to the abductors. It registers in their differentiated capacities to handle the potential captors. The narrator reveals that Jasiri initially rejects Joan’s warnings. Their conversation erupts in a serious altercation, which even includes a few exchanges of slaps and requires an intervention from TC (Teacher Clemence). However, when Joan later convinces Jasiri of the pending danger, again reminding him of an unnamed and previously murdered boy with albinism, this convinces Jasiri of Joan’s good intentions, because she says the other boy might have lost his life, “but [Jasiri] still [has his]” (13). Jasiri’s realisation of the true danger is depicted in these terms: “The words hit [him] like a heavy blow again. He put his forehead in his palms [...] Fear made him break down” (13). Here, the conceptualised fear highlights Jasiri’s awareness of his vulnerability, which he had attempted to deny through the rejection of Joan’s earlier warnings. Jasiri’s reaction hints towards the connection between vulnerability and the absence of agency. The act of “break[ing] down” suggests Jasiri’s resignation and helplessness and invokes Butler’s question about the agency of vulnerable subjects, which she raises in her study, “Rethinking Vulnerability and Resistance”, as follows: “Does the discourse of vulnerability discount the [...] agency of the subjugated?” (22). Butler’s question implies that one’s vulnerability in perilous situations can actually be a motivation for saving one’s own life. However, in Mutani’s representation, the subjugated, Jasiri, is deemed lacking the readiness to act to protect himself. This claim is emphasised when Joan tells Jasiri: “You need to be strong. Protect yourself and be a hero” (14). In this moment of narration, one questions

Jasiri's ability to act and to defend himself. Granted, the narrative focus returns to Joan who comforts Jasiri like a mother: "You can survive this if you follow my advice. Then we shall become friends" (14), and he realises that "[h]e must trust her with his life" (14). This emphasis in the original underscores a signification that links *Human Poachers* with "fiction's fascination with [...] representational history in which childhood and disability" signal the "markers of the helplessness" or persons "wholly dependent on [other's] powers for their" survival (Barker 6). In line with the thinking of Butler et al., the narrative seems to imply that vulnerable figures are dependent upon and subject to the help of the invulnerable, for they cannot act in their own behalf. Barker's propositions appear to be true in Jasiri's case. As a child, Jasiri is engrossed in fear and terror caused by the pending danger he might face and so his reaction, to surrender to Joan's help, is a natural one. Again, the narrator does not comment on this assertion. Thus, put against Joan's bravery, Jasiri's helplessness exhibits what Yenika-Agbow terms as the failure of the narrative or rather the narrator to establish a "dialogue of equality" (*Representing* 114) between the characters with and without albinism. Indeed, Mutani's representation marks the two children as having different bodily capacity. And lastly, the emphasis highlights the writer's 'girl empowerment' agenda at the expense of the agency of the protected boy. That fact frames Jasiri as a figure without choice and as capitulating to the benevolence of an intermediary agent (Joan), the person who strives for his life on his behalf. The representation signals Mutani's failure to represent children with bodily deviance as "sentient agents [...] with alternative narratives" capable of "dismantl[ing] stereotypes of helplessness, passivity and tragedy" (Barker 14-15). I argue that such a portrayal is contrary to an *ubuntu* maxim, which requires that one helps people to affirm themselves as human and not to expose their difference (Mokgoro 15). Unlike Joan, Jasiri seems to lack a sense of agency and subjective awareness of the need to initiate and implement plans to protect himself against the pending danger.

In contrast, Joan's promise to save Jasiri's life signifies her determination and self-confidence in her ability to save the boy who lacks agentive attributes. With this framing, I am reminded of Siebers' assertion that a body deemed perfect is always thought of as capable of "adjust[ing] to new situations" while a deviant one is "limited in what it can do" (11). Thus, when Jasiri accepts Joan's creativity or "advice" for his survival, and leaves matters concerning his life in her hands, the way the agency of both children is perceived by an audience is impacted. The visualisation hence frames Joan's body as one capable of influencing the quality of Jasiri's life because, as we have seen already, "fear" of the abductors had broken Jasiri down. His defence has been compromised to such an extent that it is difficult for him to exercise agency. Since this imaging seems to represent children with albinism similarly to what Barker calls "objects of

[...] patronage”, without agency, voiceless and in need of compassion (13), it also implies that albinism is specifically an emblem of victimhood and helplessness, suggesting that Jasiri’s body is thus disabled, seen as a body that lacks “the capacity and desire to strive” (Siebers 9). Although these traits might seem as though they are momentarily disabled by Jasiri’s fearful state, they imply a narrative configuration that marks Mutani’s altruism as an obstacle to his ability to reconfigure the construal of albinism as a weak form of humanity. Instead of freeing the disenfranchised child with albinism “from [narratives of] domination”, the very thing African literature confronts via its “search for a common identity” (Gikandi xi), Mutani’s narrative seems to emphasise Jasiri’s passive personhood as compared to Joan’s dynamism, irrespective of the fact that the children are of the same age.

We further witness more evidence of hegemony in narrative events describing Joan’s mission to save Jasiri. On the same day that Joan warned Jasiri of the pending danger, the abductors went to his home. Fortunately, Jasiri had already run to the head teacher’s house for safety. Eventually, the abductors confronted Berita, who in her terror “threw the kerosene lamp [at them]” to defend herself (17). Unfortunately, this incident caused Berita’s house to catch fire and she fell on the “floor and passed out” (17). Fortunately, Joan and her peers succeeded in putting out the fire and rescuing Berita. Undeniably, Joan’s success in warning Jasiri and rescuing Berita from the fire, cement her bravery and teaches a child reader to show the “humanistic orientation towards fellow beings” (Makgoro 16). However, events that follow these acts of saving Jasiri and Berita foreground the way altruism is employed to demean the saved body, further framing it as less agentive than Joan’s.

For example, soon after the fire accident, the narrator focuses on the scene in which Joan’s grandfather confronts Jasiri with questions and comments, inviting us to rethink Jasiri’s dependency on Joan. Their exchange proceeds as follows:

“You must be a strong boy,” the old man said and patted Jasiri. “Did you pull your mother out of the fire by yourself?”

“No, I ran away.”

“Oh, I see.” The old man was surprised. He continued to examine the dirty brown cotton sack he held. “Whoever saved your mother used this sack as a shield.” Jasiri looked at Joan but said nothing.

“Why didn’t you fight the bad people who came to burn your house?” he asked again.

“They didn’t come to burn our house,” Jasiri explained. “They came to carry me away.” (25)

This dialogue presents us with an ambiguous situation. At first it depicts Jasiri as a weakling, lacking in proactive capacity, while Joan emerges as a heroic and daring character. Again, the dialogue suggests Jasiri’s cowardice, implying that he “ran away” and “did [not] pull [his] mother out of the fire by [himself]” (25). Here again, chances are terror, and not albinism, might have motivated Jasiri to act the way he did. There is no way he could have confronted the enemies while fearing for his life. Yet, the description might invite one to think about the bravery of the figure that saved Berita, narrated in TC’s comments on Joan’s heroism: “the man who saved Berita [seems a] hero in this drama” (25). Here, terms like “the man” and “hero” evoke Butler’s idea that a “discourse of protection” can be “hegemonic, undermining and effacing [...the protected figure’s] agency” (Butler et al. 6). These terms presuppose Joan as both masculine and brave, and by implication portray Jasiri as egoistic, imprudent, irresponsible, unassertive, and lacking *ubuntu* virtues. A person with *ubuntu*, Ramose avers, must always demonstrate the concern for others—to care for them (“Globalisation” 752). Yet Jasiri is depicted as lacking that characteristic. This lack emerges when the narrator juxtaposes Jasiri’s decision to run for his life and “[leave] his worried mother behind” (33). When noticing “his mother’s house on fire [...] he felt guilty for not warning Berita” (33). The narrator reminds readers that, although Berita loves Jasiri dearly and had always protected him, yet upon sensing the pending danger, Jasiri disappeared, without considering Berita or alerting her to the danger (17). Recalling these incidences, the narrator “act[s] as a witness or a judge of” Jasiri’s “character and behaviour” (Valle 294). Such narration reminds one of Siebers’ view of representations of human differences, especially the myth that disabled people lack in thoughtfulness and social skills, they are self-pitying, and cannot “invest energy in other people” (40). With these ideas in mind, the narrator’s recollections may, in addition to Yenike-Yagbow’s suggestion, perpetuate stereotypes regarding children born different (17), because the narrator seems to judge Jasiri as being recklessly inconsiderate. Had he thought about Berita’s wellbeing before running to the head teacher, he would have warned her, and both could have acted appropriately. This lack of thoughtfulness creates suspicion about Jasiri’s intellectual ability and exacerbates the myth that people with albinism are *zero-zero/empty-headed*. Yet, criticism can be levelled against this interpretation for there is always an ethical dilemma when one should consider serving themselves or others first when sharing a perilous encounter.

Even with this ethical dilemma, Joan's mission to save Jasiri's and Berita's lives invites a considerable number of interpretations. For example, the scene that comes after the fire accident markedly suggests how the narrative shifts the focus from the importance of saving Jasiri, to Joan, who brags about not only saving Jasiri but being able to use her acts of bravery to befriend him. What startles us is how the narrative signals that Jasiri's vulnerability was exploited to profile Joan's sense of superiority. Through saving Jasiri, Joan brags: "my name should be written in the books of history" (27). She furthermore asks: "who else has done more than me today?" (27). It is true that Jasiri was cornered in an injurious situation and so he must have accepted the help of Joan. However, it is also inhuman for Joan to exploit such a situation to profile herself as more capable than anyone else or rather more heroic because this profiling implies the vulnerable Jasiri has become Joan's means to an end – her self-gratification. As Didier Njirayamanda Kaphagawani's explains, people born different are often "viewed" in Africa "as non-people – as not *abantu* (people) but *izinto* (things) that can be conveniently abused and exploited as expendables for one's self-gratification and denied the right to fully flourish as human beings" (207-208). Put simply, Kaphagawani can be understood as saying that some Africans deemed 'normal' regard those born different as objects they can manipulate for their personal fulfilment. Given this explanation, one wonders whether Joan's self-commendation is configuring Jasiri's body as the one that is atypical therefore ineffective. Such configuration does not, as per *ubuntu* virtues, affirm Jasiri as a normal child, neither does it frame Joan's altruism as serving humanity in the *ubuntu* sense. Rather, it appears as an act of self-gratification. Of interest is Joan's demand for the immortalisation of her name, by which she seems by implication to associate herself with the discourses of hegemony since she can act for the incapable one, Jasiri.

Even so, there are moments in the narrative that indicate the potential of the story to refute the undermining discourse of protection, but again, they are countered by unfolding events that perpetuate Jasiri's insecurity and further highlight his inability to act for himself. For example, the next day after the fire episode Jasiri goes to school. While learners are gathered at the school assembly, listening to the school principal, the omniscient narrator gives us a peek into Jasiri's mind, as he drifts off into a daydream, imagining

himself as an eagle with wings, flying up the sky and away from the hunting squad. He was happy to see enemies far below him. He snatched to safety all children who were in danger. He went to fight his enemies. He gouged their eyes out. Their faces were covered in blood. Jasiri smiled. He was daydreaming. (31)

Garnered from the dream is Jasiri's desire to be free, safe, and strong, and to determine his own life course. Collium Banda, in "Ubuntu as human flourishing? An African traditional religious analysis of Ubuntu and its challenge to Christian anthropology", explains how one may "authenticate [...his/her] human personhood" as per *ubuntu* qualities (207). According to Banda, one does so through acting as "a truly virtuous person" (207), the quality depicted when Jasiri dreams of taking care of all endangered children, to defeat "the hunting squads", and to serve as a protector of others — to act autonomously and contribute to the humanity and well-being of others. That agential desire is contrary to his position as the recipient of others' help. Ironically, Jasiri's daydream remains exactly that – a dream – because in the rest of the narrative he remains the receiver of protection, especially from Joan.

Related to the dream is another moment where Mutani hints at Jasiri's yearning for self-determination, a desire to act for himself, and to be like other children. For instance, after being scolded by his mother for staying out late, playing football with his friends, the narrator says: "Jasiri decided it was time to change certain things in his life" which implies his desire "to live like other children in the village. He knew he was different but wanted to be treated like them" (47-48). In short, Jasiri "wanted to live a normal life" like Joan (47-48). Although this diction reveals Jasiri's mental understanding and agentic self-awareness – the feeling that he can make things happen in his life – his reference to Joan signals how his desire for an agentic self is repeatedly undermined in favour of Joan's heroic role, as she acts to protect and save him. Besides, Mutani does little to involve Jasiri in actions where he can develop his personal efficacy, and instead constructs Joan as agentic. That depiction implies that Mutani's conception of altruism is one that associates vulnerability with lack of agency (Butler et al. as cited earlier). Juxtaposed to Joan, Jasiri is denied that which Joan is capable of — acting for the self, a defining feature of agency.

We further identify such denial in other narrative events where Jasiri is forced to comply with Joan's decisions and her parenting roles. Such compliance affirms Berita's observation that Jasiri "can't protect [himself]" (46), a point reinforced when Joan continues to play the controlling role in Jasiri's life. Notably, after the first human poachers' attempt to kidnap Jasiri failed, Joan sought aid from Master Lwanga. Jasiri then sees Joan talking to Lwanga and afterwards disappearing into the forest. At that moment, Jasiri's determination to take part in his own safety is awakened. He had hoped to be part of the plans regarding his own safety. Such a move signals Jasiri's desire to act for himself, thereby reminding us of an earlier cited assertion that vulnerability can also be empowering (Butler et al). Again, such an urge is undermined by Joan who challenges and rejects Jasiri: "Why are you following me?" Claiming

his agency, Jasiri's responds: "I saw you talking to the master [...] and I know you've come to meet him again" (102-103). Joan responds: "Maybe but that's none of your business" (103). This response symbolises how Joan's overpowering character denies Jasiri participation in his own affairs. As per *ubuntu*, Joan's altruism (citing Banda) "expresses a limited vision" in signalling that the two children can flourish together only because her altruistic agenda, as I pointed out earlier, "discriminately favours" her self-gratification "over the welfare of" Jasiri (207). As the protector, Joan ignores the interest and desire of protected subjects to take charge of their own safety. She thus "fix[es]" Jasiri in a "position of powerlessness and lack of agency" (Butler, "Rethinking Vulnerability" 25). However, Jasiri attempts to denounce such a fixation when he demands to act directly for his own safety. He insists: "I know the two of you are going to talk about my safety [...] I don't understand why I am not allowed to come along" and "[y]ou keep me away while I'm the one in danger!" (103). He even explains how important it is for him to be responsible. He states: "I want to know what to do if your plans go wrong?" (103). Despite these attempts, Joan denies Jasiri a part in plans to ensure his own safety.

In addition to the heated conversation, Joan also orders Jasiri "like a tough mother to her disobedient son", saying: "I said go back to school" (103). The order reveals Joan's lack of consideration for Jasiri's feelings. Even so, Jasiri demands that he exercise his agency. He counters Joan's order by saying: "You are an idiot if you try to keep me away from my own safety" (103). Here again, "Joan did not wait for Jasiri to finish his sentence. She threw [him] a quick slap" (102-103), which reminds me of another *ubuntu* aphorism: "[t]he will and orientation [to dominate] at the expense of the others invites resistance which can ultimately lead to war" (Ramose "Globalisation" 754). These characters' contestations display a rather weak attempt by the author to grant Jasiri agency and to signal how Mutani's characterisation of Joan still undermines his own possible intention, namely, to accord Jasiri a sense of self-responsibility and agency. Thus, Joan's controlling nature thwarts Jasiri's agency. I read these events as reflective of Mutani's failure to imagine that "[one] is human because [one] belong[s]", they "participate [and] share" their resources for the well-being of humanity (Tutu 33-34). For Tutu, a person with *ubuntu* has the role of "affirming [...] others" instead of exposing their weakness and or differences (Tutu 33-34). In the narrative, altruism denies Jasiri a space to contribute to the world he shares with others and exposes him as different and incapable of contributing to humanity.

It seems then, by patterning Joan and Jasiri, Mutani desired to advance a girls' and women's empowerment agenda as well as one which uplifts children with albinism. However, the agenda of girls' and women's empowerment overshadows the vindication of albinism as a valid

identity. This assertion is signalled by Jasiri's overdependence on Joan, a child of the same age. Clearly, this suggested overdependence implies that it is the condition of albinism which undermines Jasiri as person. Indeed, Joan's controlling role compromises Jasiri's agency and selfhood. Thus, child readers who "find answers to their questions" in narratives they read (Yenika-Agbaw "Taking" 452), then may gain the impression that albinism renders one vulnerable, passive, victimised, and fated to be excessively dependent on the figures deemed normal, because (in Vella's words, discussed earlier) in representing Mutani's two characters in relation to *ubuntu* and discourses of protection, the narrator's "ideological position" seems to "applaud" Joan's personality and by implication "condemn[s]" or undermines Jasiri's. The discourse of protection then presents child characters with albinism as a "legible symbol for disenfranchisement and otherness" (Sieber16) and it frames Jasiri, and by implication other persons with albinism, as figures who essentially lack resourcefulness and are over-reliant on abled-bodied characters who are capable and more enterprising.

### **2.2.1 Scouting: As an Ideology of Ability**

Lastly, my discussion of the discourse of protecting and saving Mutani's character with albinism engages what I term the "scouting ideology of ability". I coined this phrase after reading Siebers' work, especially his idea of "the ideology of ability" and in reference to the children enacting the scouting motif evident in Mutani's *Human Poachers*. As highlighted earlier in this chapter, Siebers' ideology of ability points towards the tendency where certain bodies or minds are socialised as ideal forms of being human. Within this ideology, as Siebers avers, bodily ability "determine[s] human status, demanding that people with [bodily deviances present themselves in an] able-bodied [manner] as possible" (Siebers 9). Such an ideology designates an able body as effective, capable of exertion, planning and of adjusting to a new environment. Those are agentive traits that bodies and minds of people deemed abnormal are constructed as lacking and therefore as incapable of exercising their agency (Siebers 9-10). By extension, my use of the "scouting ideology of ability" refers to Mutani's deployment of child characters, children who are scouts and able to advance his altruistic agenda in his novella, in a world that I argue is one that excludes albinism as an abled identity. In the current section, I examine a position that Jasiri occupies vis-à-vis the children's scout squad characters in relation to other characters deemed normal. I demonstrate that by alluding to a scout motif Mutani signals a world where children with albinism are depicted as "embodied forms of perceived 'deficiency'" (Barker 8). By contrast, the child characters without albinism are framed as being responsible enough to assume their role as protectors/scouts and capable of adhering to the scout squad's mission, which means that they are to be the protectors of Jasiri, the child with

albinism who is portrayed as deviant. Such a portrayal, to use Barker's terms, is "masking [...] a duty of care" within a representation where the child character with albinism is constructed as one without agency and who requires guardianship from the child characters without albinism (8). That idea unfolds as follows.

Mutani's altruistic agenda is partly foregrounded by the role played by the child scouts who act on behalf of the child with albinism, protecting him. As previously mentioned, Joan and her scout squad succeed in saving Berita from the fire and scaring away the hunters. However, in my view, this technique has implications for Jasiri's character designation and agency. Apart from ensuring Jasiri's safety, the scout motif echoes postcolonial representations of children deemed deviant, one which "capitalize[s] on [the] formation of the child's docile or fragile body" to often "[emphasize] its susceptibility to disablement to heighten the sense of humanitarian crisis and to insist on the urgency of [external] intervention" (Barker 11). Barker's thoughts are meaningful regarding the narrative positioning of Jasiri in relation to the children's scout operation, whose mission is emphasised in the oath the scout squads take:

On my honour,  
I promise that I do my best,  
to do my duty to God and my country  
to help other people all times  
and to keep the Scout Law. (141)

Whereas this oath emphasizes a scout's responsibility, it echoes *ubuntu* virtues — generosity, respect and the "greatest good" (Tutu 35). It also ascertains that whoever is a scout should have agency, the capacity to contribute to the world, "to help other people all times", which reflects Mutani's effort to represent the plight of vulnerable persons and presupposes his humanistic agenda, urging the invulnerable or agentic children to help the vulnerable ones presumed less agentic. As for Jasiri, who is presumably the suffering other, the oath requires that readers think about his agency, position or role in the scout squad, which represents a place of relative safety. The squad is populated only by children deemed normal, including Joan, Salu, Egna, and Mpuya.

Granted, as we have seen, the narrative (through Joan) exempts Jasiri from participating fully in the role in the scout mission, insisting that it is none of his "business" (103). Again, through Berita, we learn that Jasiri needs help from "friends that can shield him" (16). "[W]ithout his Saviour[s]", Joan and her squad, the narrator says: "[Jasiri] did not know how to stand alone"

(124). This image of helplessness and inability to act for oneself configures Jasiri's body as ineffective. He cannot do what other scouts can do: "helping other people". His body lacks the agentic traits that would define it as able-bodied. Here again, one is reminded of how aid narratives represent postcolonial children to effectively solicit aid or support during humanitarian crises. As Barker avers, fictional portrayals of disability "often [associates somatic conditions and/or] childhood – with helplessness and victimhood" and as having to summon external help (11). This portrayal simply means child characters with disabilities, unlike those deemed 'normal', lack in agency and cannot influence the quality of their lives. Such framing is exhibited in Mutani's portrayal, which excludes Jasiri as an active scout and renders him only able of receiving the scouts' patronage. Consequently, Jasiri's body is implied to be a less abled body compared to other child characters' bodies. That way, Mutani's altruism thus implies discrimination in the way that society sees less abled members of humanity versus abled people and thus configures Jasiri as having a diminished sense of agency and humanity.

For example, there are narrative incidents that imply that Joan's scout squad operation, membership, and names of its squads, follow stereotypes that define child scouts as able-bodied, while implicitly suggesting Jasiri's body as deviant and unsuitable for scouting. In the text, Joan qualifies as scout because of her enterprising personality (referred to in the discussion of Mutani's characterisation of Jasiri and Joan). She is also labelled as a "*jike-dume*" (137), a Swahili term for a girl with masculine features: tough and daring. In a chauvinistic society like Tanzania, from where Mutani writes and where femininity signifies being handicapped, the "*jike-dume*" label envisages Joan as having a masculine able-bodiedness. She is flawless in her execution of scouting duties, for she has physical prowess, eagerness, strives for successful achievement of goals and is therefore agentic. These features are implied in the scouts' mission, which requires that a scout should help those who lack the aforementioned abilities. Given the scouts' worthy motive as hinted at in its oath, Jasiri, who is portrayed as inept, is barred from having a space in it. Consequently, the scout operation, as per *ubuntu* thinking, becomes "a paradigm about [exclusion and] othering" of certain forms of humanity (Seehawer 456). Since a person "is never a finished entity in the sense that the relational context reveals and conceals the potentialities of the individual", it means that one's "concealed potentialities" can only be "revealed whenever they are actualized in the practical sphere of human relations" (Ramose, "Globalisation" 753). In the light of this insight, Jasiri's absence from scouting activities not only dismiss his body as being passive, docile, fragile, and unfit to partake in the scout's mission, but also denies him the chance to be seen as a complete human.

While the myth of able-bodiedness is what Mutani must dismantle to signify bodily equality between children with and without albinism, the operation and composition of scout squads in his narrative fortify it. In the scout “camp”, whose mission is “to protect Jasiri”, who is himself not part of the squad (131-132), one child scout asks Master Lwanga: “Is it true that albinos are weak and not gifted?” (132). Lwanga counteracts such a myth by giving out examples of gifted artists with albinism like “Salif Keita”, a “renowned musician from Africa” (132). However, Lwanga’s example does nothing to deny the way the way that novella’s representation of the scout agenda places Jasiri as different, special, delicate and good-for-nothing, like an infant, a passive recipient of the scouts’ protection, despite his futile demand — thwarted by Joan — to be included in his rescue mission.

Such passivity is further gestured as Joan recalls how her scout youngsters’ squads are labelled and constituted to denote competence. In the narrative, there are two squads: “Lion” and “Rhino” (139) patrols. These squads must protect Jasiri by attacking his potential abductors, the human poachers, who are also described as “eagles” (139) who “snatched” Jasiri “like [they are] catching a small rabbit” (139). Here, the imagery created by the animal names of these squads depicts the child scouts as active, energetic, and powerful. Such traits signal that, like a lion or a rhino, these children have the capacity to act on behalf of Jasiri (imagined as a small rabbit, hence powerless). The rhino and the lion are agentic and have bodily ability to attack the “eagles” (abductors) that victimise the “small rabbit” (Jasiri). Furthermore, the image “of a small rabbit” implies that Jasiri is a cornered prey or an ailing patient and therefore in need of scouts’ altruism. By contrast, the children who are scouts are imagined as brave and stronger — lions or rhinos. The child reader is likely to conceive Jasiri as “an abnormal child” (Achufusi 175) whose body needs permanent guarding, unlike other children in the narrative. Besides evoking the urgent need to help children with albinism, such representation denies Jasiri status as a normal child. One might ask: why is Jasiri unable to participate in the other childrens’ actions on his behalf? One of the responses to the question presupposes that he simply does not have the capability to act like other children of his age. Thus, he is a mere recipient of others’ help. For example, by the end of the narrative, we see Joan and the other scouts, after many ordeals and after defeating the abductors, finding the abducted Jasiri in a cave, seemingly lifeless, tied to a stone slab that “looked like an altar” (150). Joan is the one who cuts the ropes and tells her peers to pour water “over the head of the fainted boy” (151). The image of an apparently lifeless Jasiri, being revived and rescued by these scouts, highlights that they can help others, including the less agentic like Jasiri.

Mutani's inclusion of the scout ideology as a significant narrative act supposedly encourages humane socialisation, moral behaviour, such as helping children with albinism, and conveys a signal to the world about children and *Ubuntu*. There are many other children lacking agency who need to be approached according to its tenets: scouts undertake to affirm the humanity of their fellow human beings by being "open and available to others" (Tutu 31) but scouting in Mutani's text appears to position the children with albinism as victims who are overly dependent on proxy agents. Consequently, as a technique of representation, scouting evokes many questions about vulnerability, agency, and stereotypes. Its narrative framing and plotting highlight a form of literary ableism that denies the body of a PWA favourable cultural meaning. Hence, although Mutani seemingly intends to tell the child readers that "someone with albinism is like any of [them]" (131), he seems to endorse the view that albinism entails powerlessness, passivity and/or a state of bodily disablement. Such framing denies Jasiri an agentic personality, i.e., as having the "possibility of acting for oneself" in his life (Butler, *Account of Oneself* 87). Mutani's children's scout agenda then is opportunistically promoted to strengthen the personality of other children without albinism and in turn frames albinism as an emblem of helpless bodies.

### **2.3 Vulnerability, Altruism and Agency in Nahida Esmail's *Living in the Shade***

As I turn to Esmail's *Living in the Shade*, I continue to explore matters of agency in relation to characters with albinism and analyse how agency is aligned with an altruistic agenda. I argue that in imagining vulnerable children with albinism and their capacity to act as agents of the self, Mutani's and Esmail's representations demonstrate both similarities and differences. These authors typify the figure with albinism as one who is overwhelmed by endangerment, so that their wellbeing and their ability to exercise personal and social agency depend on contrived philanthropic strategies or sympathetic characters to help them. As expounded, Mutani's philanthropic agenda largely disregards the character with albinism's personal agency. In my view, however, Esmail's philanthropism (as I shall demonstrate) alludes to charitable plans devised by individual and collective efforts, made by people with and without albinism to affirm *ubuntu's* thinking, that "one can only reach the fullest self [...] through and with others" (Krog 355). Indeed, through acting with others and accepting the support and help from various generous characters, I see Tatu, Esmail's protagonist as successfully emerging an agent of the self by the end of the narrative.

The current sub-section thus inquires how Esmail's use of Tatu's first-person narration and other rhetorical strategies function to complement her inner reflections as she deals with the socio-cultural and environmental conditions that impair the agency of children with albinism,

and the challenges they face in achieving autonomy and personhood. The section first examines how the narrative perspective and the theme of vulnerability complement each other to elucidate the protagonist's understanding of her compromised position at home, at school and in other public contexts, as shaped by her interaction with other characters. It further considers how such clarification acts as the protagonist's way of voicing her appeals to the public. Lastly, the section explores Esmail's configurations of the personal and social agency of her child protagonist. The focus is on the motifs of philanthropic conduct as advanced by individual efforts and the deployment of the humanitarian NGO and its ideology of charity as a technique of representation. My interpretation maintains that Esmail imagines her protagonist as one overwhelmed by socially and materially imposed vulnerability. She therefore voices an appeal to her public readership to identify with the altruistic characters who advocate for an inclusive society where Tatu is reconfigured as a social agent and an agent of the self.

In *Living in the Shade*, Tatu, a female child with albinism who is the first-person narrator, talks of her experience of living with her mother (unnamed) and her loving, kind neighbour — Mama Mkubwa. These are among the few figures with whom she closely interacts in a community where she is cast out from society — a state Garland-Thomson would link with being “denied full citizenship” in “the public sphere” (“Misfit” 602”). Tatu reveals this situation as she recounts her school experience. Here, she speaks of her bully teacher, Mrs Pili, and of her fellow pupils, including Neema and Grace, whose treatment of her impedes her efforts to achieve agency. They even go as far as additionally threatening her that she might be “harmed or even killed” by evil people who earn “money by selling body parts of persons with albinism” (41). She narrates these circumstances as though she is pleading for someone to act on her behalf. However, as I shall show, Esmail signals that the moral support Tatu receives from characters such as Mama Mkubwa energises her to act for herself. Furthermore, Mama Mkubwa's role complements Brother Karimu's and Sister Julianne's, whose NGO supports interventions that accord Tatu what Gambetti calls “a common world” (28) that respects human diversity. As per Ramose, that world would be one with “establishe[d] humane respectful relations” among individuals (“Globalisation” 753) — the world that accommodates Tatu as a normal child amongst her peers where she enacts her personhood. Generally, Esmail's novella seems to suggest Tutu's amalgamated view of Christianity and *Ubuntu*, namely that “God has made us so that we will need each other” and that “persons are ends in themselves only through the discovery of who they are in others” (81). This supposition echoes individual and collective efforts that, as I shall establish, contribute to Tatu's sense of self-worth and agency. Tatu's tale is thus one of the “stories” that the African literary critic Grace Akinyi Ogot says, in “The Role

of Women in African Literature”, “encourage and inspire the youth [...]” to act for their wellbeing and that of others, a counter narrative to many “modern East African [stories which portray] a woman as a loser, unwanted being” (24). This assertion unfolds in the following sections as I discuss how Tatu’s narrative voices her appeals and how the motif of altruism signals the upliftment of the marginalised child whose identities —as a woman, and as a child with albinism — render her a victim.

### 2.3.1 Narrating the Self, Voicing Appeal

In *Living in the Shade*, Esmail’s use of the first-person narrative clearly implies literary advocacy on behalf of children with albinism in their quest for agency. Regarding this technique, Esmail takes an already marginalised figure, a female child with albinism, Tatu, whose skin colour renders metaphorical and social invisibility and places her as “a visible, fictive ‘I’ who interferes in his/ her account as much as s/he likes, or even participates as a character in the action” (Bal 17-18). As the “character in the action [of narration]”, Tatu not only narrates her situation but also connects with her readers. Consequently, she inserts several appeals to readers. Upon reading her story, the reader feels as though they are being directly addressed and/or provoked to empathise and/or even act on her behalf.

As Tatu’s narrative begins, she immediately invites us to hear via her homodiegetic narration that she is an innocent child facing an existential crisis. Here, the reader encounters the voice of a child narrator crying out while having a nightmare: “Please, don’t. Please, leave me alone! I haven’t done anything to you. I am only a child!” (1). This nightmare brings to mind Sabsay’s explanation, as expounded in “Permeable Bodies: Vulnerability, Affective, Power and Hegemony”, that a vulnerable figure is mostly imagined as “the suffering other”. As signified in the opening chapter, this inhuman treatment of children with albinism is what Tatu alludes to, as the helplessly “violated, or deprived body [that] demands affective” humanitarian responses (Sabsay 180). Communicated here, via this “I”-narration, is an image of an innocent child character with albinism, who implores others to help in reversing this situation. The voice thus not only informs the reader that Tatu is a normal child with normal feelings such as fear, but also encourages readers to empathise with her situation. As the literary critic on narrative empathy, Suzanne Keen, asserts in “Theory of Narrative Empathy” (2006), our empathy “can be provoked by witnessing [...] other’s emotional state, by hearing about [their] condition, or even by reading” about their situation (208). Evoking empathy is thus Esmail’s way of getting the reader to recognise Tatu’s suffering, keeping in mind the *ubuntu* ethics of care, because as one reads about Tatu’s ordeals, one experiences what Keen calls “emotional contagion” (209). Such an emotion stirs readers to share the emotions that Tatu endures. Readers can imagine

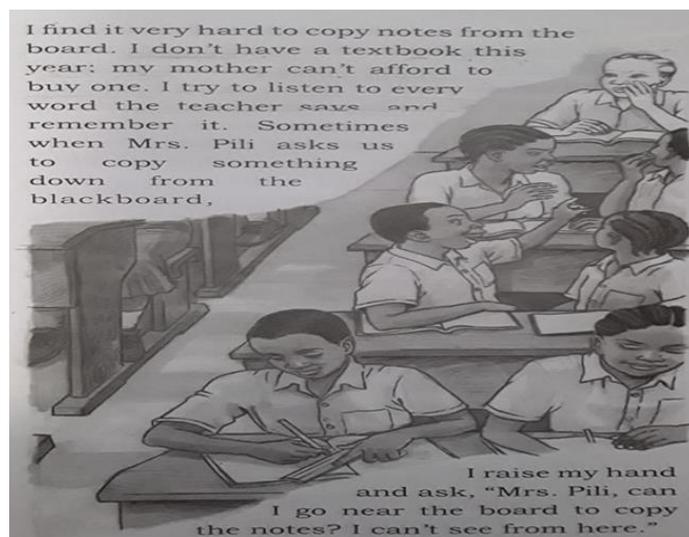
stepping into the shoes of the protagonist and identify with her situation. Accordingly, the readers' awareness that "people live through the help of others" (Mokgoro 17) is summoned. This emotional identification is amplified, especially when Tatu tells more of what she dreams: a threatening manifestation of "a dark hand that held a machete in front of [her]" (1). This fearful image is followed by yet another life-threatening declaration: "I want your limbs" (1). The rhetoric here alludes to real situations in which the humanity and personhood of people with albinism are discounted, through killings and mutilations of their bodies. Tatu is thus depicted as a "[child who provokes meditation] on the politics of care and whose [vulnerabilities] generate suggestions for [...] a [re-]configured 'healthy' community" (Barker 26). The notion of a healthy community here recalls Swanson's earlier cited idea, that the *ubuntu* spirit requires people to cooperate, help one another, and proclaim a humanity that transcends differences.

Since Tatu is a child, the act of narrating her own story via the first-person narrative perspective not only frames her as the "agent" who "relates a story" but also as a figure who is afforded the capacity to speak (Bal 5). She strategically exploits such agency to implore the readers to consider her situation. This is because, in children's narratives, such a perspective is a means through which the character pleads with "readers [...] to align themselves with [her] point of view" (Stephens 64). Thus, by voicing her perilous circumstances, Tatu conveys how traumatised she is and, as implied by "her tearful eyes" (1), and in the plea, "I am only a child" (1), she positions herself as a guiltless child, overpowered by her circumstances. This plea, to borrow terms from the critic of children's literature, Grace Ify Achufusi, sends the message that, besides having the condition of albinism, Tatu is just "[a] normal child" who knows "her right" to live (176), but she is overwhelmed by her circumstances and hence she deserves compassion. Here, as in Mutani's narrative, Esmail's representation implies a conformity between Tatus' tale and narrative techniques, which (according to Barker) "often rely for their impact on overdetermined associations" of bodily deviances – or "childhood – with helplessness and victimhood" to attract humanitarian assistance (11). For example, the image of Tatu's helplessness and victimhood is amplified by the description of the child crying before the hand holding a machete which threatens to chop off her "limbs". A reader is fully alerted to the magnitude of the dilemmas Tatu might encounter and her fear. The image also signals that she has a limited capacity to act against these circumstances. She is "only a child". She needs someone to act on her behalf, the point I shall return to as I discuss the motif of philanthropism, which I argue signals such a proxy agency.

In the meantime, I wish to focus on how Tatu's narrative reveals her social vulnerability, which impedes her agency. Much of the rejection that denies Tatu's agency and disregards her humanity is narrated as she describes her circumstances at school where she reveals the levels of insult and discrimination, she must endure from both her peers and teachers. In describing her school, Esmail effectively paints an image illuminating the ghastly conditions of Tatu's educational environment with its "shabby, worn down" appearance and "[b]roken and shattered windows" (3). This ugly image features not only the school environment but also the people who undermine Tatu and inhibit her agency. She equates going to school with "getting ready to face a gloomy day" (2). The melancholy voiced here shows Tatu's discontentment with the disabling school environment. She visualises how her school and classroom atmosphere, especially her relationship with her peers, Grace and Neema, all contribute to her predicament, as follows:

I don't have friends at school, but this is not because I don't want any. I really like Grace and Neema. I wish they would want to hang out with me. Unfortunately, they never want to be seen near me. I have a place in the class at the back near the window. No one wants to sit with me. They think I have got some sort of germs that can harm them. I don't know why they think that. If they knew me, they would realise I am just as human as they are. (2)

These quotations frame Tatu's classroom as a community that lacks *ubuntu* virtues. Such is a community without the spirit of "caring, sharing, hospitality", "compassion, empathy, honesty, humility", and friendship (More 156). It also implicates Banda's expressions that, when "Ubuntu as relationality" diminishes, "a good ground for human flourishing" such as "interdependence, communal support, communal networking and communal security that is needed for other people to thrive" are also diminished (210). Without such a ground, one's agency is compromised, for such persons become misfits. That is, when the "world fails" one's "flesh in the environment one encounters" (Garland-Thomson "Misfit" 600), one is subjected to "injustice and discrimination" resulting from "the materiality of the world" and "social attitudes or [...] practices" around her (Garland-Thomson "Misfit" 593). According to Garland-Thomson, the situations conducive to becoming a misfit happen in the same way as it does when one enters "a boardroom full of misogynists" or "a whites-only country club" (Garland-Thomson "Misfit" 600), hence (like Tatu) one becomes isolated and one's social agency is thwarted. Tatu's classroom atmosphere (see figure 3), exposes this lack of support as enhanced in her sad tone: "No one wants to sit with me", which conveys the point that she is socially unsupported by her peers.



**Figure 2: Tatu's classroom**

The unsupportive environment, according to Butler, impacts on one's "capacity to exercise most basic rights" ("Rethinking Vulnerability" 15) and in *ubuntu* thinking it obstructs one from fully realising one's humanity because "a person is truly human in the context of actual relations with other human beings" (Ramosé, *African Philosophy* 93). Implied here is the point that through relationships with others, individuals affirm each other's identities. Also, without others, one's social agency is imperilled. The learners stigmatise Tatu's skin condition, albinism, and that obstructs her capacity and inhibits her desire for friendship. Eventually she has no one "to hang around with" (2). The situation reflects how "exclusion from the public sphere" or shared space (Garland-Thomson "Misfit" 594), of people born 'different' may frustrate their social capacity and prevent them from enacting their identity. If "[b]eing human in the sense of Ubuntu" is "being intertwined with others" (Seehawer 457), then Tatu's capacity for being human is jeopardised. Within her small classroom, as the quoted paragraph and figure 3 reveals, Tatu is relegated to its margin, at "the back near the window" (2) — analogous to how people with albinism are pushed to the fringe of society.

However, one point to consider regarding Tatu's narration of her classroom conditions is how the diction indirectly signals an appeal for someone to intervene in her situation. The appeal registers as she says: "If [my fellow pupils knew me and my condition], they would realise I am just as human as they are" (2). According to Garland-Thomson, such a telling may infer an "intense awareness of social injustice" resulting from being a "misfit" ("Misfit" 594), as Tatu is seen. This is why she expresses her need for a society with *ubuntu*, one that makes "demand[s] for respect for persons no matter what their circumstances may be" (More 157), where people could treat her with respect as an equal. Such equality, again calling to mind Garland-Thomson, might bring "a state of correct synchronization with [her] circumstances" ("Misfit" 594). The

narrative thus pleads that awareness regarding albinism be raised amongst Tatu's peers so that she could be accommodated and make friends or amicably 'hang with' Neema and Grace, her favourites. If they were aware of the nature of albinism, the pupils, and by implication readers, may avoid using terms such as “stupid, blind *zeruzeru*”, “whitie”, “freak”, ‘ghost kid’ ‘diseased child’” and other labels employed to stigmatise children with albinism (6-7). Albinism has been framed as contagious, possibly thereby fostering the learners' hostility towards Tatu and thus defeating her social and personal agency. However, as explicated in the later section, once the learners have been educated about the condition, they would cease to subject Tatu to name-calling and other forms of ill-treatment because of her albinism such as when an older boy “punch[es her] in the face” because she “refused to give him [her] food” (7); when “the big girl near [her]” confronts her with “curious stares”; and lastly, when “[other girls] look at [her] and sneer” while whispering and nudging (4). Even so, what is important here regarding Tatu's recalling of the abuse she endures and wishes to come to an end, is how Esmail signals that Tatu's ill-treatment is being instigated by perpetrators who are “older” and “bigger” than herself, and how in any event, there is no one to rescue her (7). So, when Tatu, who amidst these crushing conditions, resorts to saying: “No one helped me” (7), she indirectly signals the need for a proxy agent who will act on her behalf to reform the social environment which disregards her individuality.

Tatu's expression that, despite being at school, “No one helped [her]” (7) deserves further consideration. This reflection not only implies that one needs “enough support for [him/her to] exercise [...] freedom” (Butler, “Rethinking Vulnerability” 14), but also inspires us to think of the possibilities of intervening in perilous conditions that vulnerable children do encounter. It is thus the expression through which Tatu questions the structures and perceptions that restrict recognition within the school context and leads to her exclusion because of her bodily particularities. One questions the role of the authorities within Tatu's context and question whether any attempts are made to “accommodate[e...] the widest possible range of human variation” at school so that her social wellbeing could be granted (Garland-Thomson, “Misift” 594). In Mutani's *Human Poachers* it was clear that the authority figure, the village chairman, undermined Jasiri and was complicit in attacks against albinism. Such framing signals “a possible loss of Ubuntu in today's Africa” amongst some Africans (Seehawer 56). In a similar fashion, Esmail's text evokes the failures of the social system in not protecting the vulnerable child, Tatu — an example of the further erosion of her agency.

Supposedly, a school is a place where good teachers help learners to become independent and responsible individuals in their lives. However, Esmail describes Tatu's teacher, Mrs Pili, as

unfriendly, dehumanising Tatu and undermining her agency as learner. In her inner reflection, Tatu substantiates this assertion when she says: “I don’t like school much. If I didn’t dream of becoming a teacher, I would’ve asked mother to stay home. Mrs Pili doesn’t really like me” and she “picks on me and makes me uncomfortable” (2). In this connotation, Mrs Pili, who should have signified the school as “a democratic public sphere” (Garland-Thomson “Misfit” 601), stands for an oppressive environment which hampers Tatu’s learning competence. She is incapable of accommodating differences in learners’ needs. For example, Tatu has weak eyesight and asks permission to move to a front desk where she would be able to copy notes from the blackboard, but Mrs Pili behaves inconsiderately, saying: “you stupid, blind *zeruzeru*, copy what you can and leave the rest” (6). Additionally, she canes Tatu (6), and this act evokes “giggles from the pupils” (6). This detail signals that the figure who should endow Tatu with a sense of social harmony so that she can enact her citizenship among other learners is actually a perpetrator of injustice. Ironically, Tatu needs an agent other than her teacher to intervene in the case of her so-called carer’s cruelty. Clearly, the authorities around her are incapable of promoting that which Letseka describes as the appreciation and tolerance of human differences (“In Defence” 56) — one of the maxims of *ubuntu* in terms of which Tatu’s bodily difference might be accommodated. Such depiction signals how social institutions may compromise the agency of children with albinism, perpetuating their suffering. Suzan Dodds, in “Dependence, Care, and Vulnerability”, a chapter in *Vulnerability: New Essays in Ethics and Feminist Philosophy* (2014), (edited by Catriona Mackenzie, Suzani Dods and Wendy Rogers), talks of children’s vulnerability which results from “circumstances where [...] children are in dysfunctional relationships with their [...] carers” (192). According to Dodds, the poor relationship between a carer and a child (who is presumably vulnerable) may lead to a situation where “the development of [the latter’s] capacities is neglected” (Dodds 192). Once this happens, it affects the child whose “dependency is exaggerated” (Dodds 192). This is the situation alluded to in Esmail’s tale. Evidently, Tatu goes to school because she dreams of becoming a teacher. This desire shows a claim for agency, to become useful and independent. However, the perilous school environment, devoid of what More calls “an understanding — a societal bond” and “the basis for consensus” (157), sabotages Tatu’s pursuit of her dreams. She thus remains hopeless with none to lean on or to endorse her agency.

This hopelessness is reflected in another narrative event where Esmail again gives us insight into Tatu’s inner thoughts, making an appeal for the reader’s sympathy. “What wrong have I done to be treated like this? Am I cursed?” (7). She even appeals to a higher being in one of her moments of depression. She asks: “I am an African. I am a child. God, have you forgotten to

bless me?” She then addresses the general listener or reader: “I feel that God has blessed Africa and its people but has forgotten me. Is that the reason I don’t have any friends?” (4). The religious context here hints that Tatu is totally without recourse and that she succumbs to internalised stigma. She has surrendered to the belief that God might have cursed or ignored her. This and several other appeals made by Tatu compel the reader to reconsider the urgent need of accommodating albinism as a human variation. Such an accommodation requires the restoration of what Tutu, as cited earlier, calls “social harmony”. It might require a rearrangement of material and social conditions so that Tatu achieves that which Garland-Thomson calls a “positive way of being and positioning based on an absence of conflict” (“Misfit”594). Social harmony is the condition that might enable “the self” fundamentally to be “a part of the community” and where “the self is dependent on other selves and is defined through its relationships to other selves” (More 157). We can thus consider the novella as proposing that, since Tatu is too young to subvert the situation by herself, there is a need for “concrete social policy regarding such issues as shelter [...] and legal status” to negate, reduce or contain her vulnerability (Butler, *Frames of War* 13). Thus, a reshuffling of social cultural practices is needed to reconstruct conditions which produce segregation, and which also undermine her. The task, as demonstrated in the coming section, needs resourceful agents and collective efforts capable of revolutionising people’s attitudes towards albinism. In this case, the change needs to happen in Tatu’s neighbourhood and at school. This point reminds us of Jasiri’s protection by the scout squad in Mutani’s text.

Up until this point, we read Tatu’s narrative as revealing her insights into the quandaries of her social environment, proceeding to reveal how these dilemmas undermine her agency and to cast her as vulnerable. There is evidence in her narration that signifies her propensity for personal agency. She desires to break free from the restrictions that frame her as someone without the capacity to overcome her vulnerability. When she refers to her status as a child and her helplessness, she highlights her incapacity and the failure of others to help her. That rhetoric implores those other characters who are able to do so, to intervene in situations facing children with albinism because, as Keen asserts in *Empathy and the Novel* (2007), “many readers report that novels in which child characters are subjected to cruel or unfair treatment evoke empathy” (69). Hopefully, this sympathy might urge readers to feel as though they are obliged to act on behalf of the subjected child. As per *ubuntu*, social wellbeing is threatened or “diminished when others are humiliated” “tortured or oppressed or treated as if they were less than who they are” (Tutu 35). A community is responsible for a healthy society. The point is evident in the following discussion.

### 2.3.2. Altruistic Intervention and the Agentic “I”

As one reads *Living in the Shade*, particularly noticing how Esmail affords agency to her character with albinism, it is evident that the tale endorses ideas put forth by scholars such as Siebers and Garland-Thomson. Such ideas demand social inclusion of marginalised and disempowered individuals as a prerequisite for their social and personal wellbeing. According to Siebers, that inclusion is possible once people’s attitudes and “the built environment” which “remain[s] as a survival of discrimination and an impenetrable barrier” to communal “participation of” people with albinism are revised (234). Without this, minority individuals’ autonomy and agency may remain restrained. This idea resonates with an observation that once a person is sustained by their environment, they “reasonabl[y] fit in” and can “navigate the world in relative anonymity” because they are “being suited to the circumstances and conditions of the environment, of satisfying its requirements in a way so as not to stand out, make a scene, or disrupt through countering expectations” (Garland-Thomson, “Misfit” 595). Combined, these scholars’ respective ideas presuppose that, for anyone to attain their humanity, they need an “intertwinement”, a state of being immersed amongst others, “that makes ubuntu transformative as there is always more work to do together in shaping our future” (Seehawer 457). *Ubuntu* always insists on the maintenance of harmonious interaction “for people to engage in mutual aid” and to “act in ways that are reasonably expected to benefit each other”, bring about social equality and affirm each other’s humanity (Metz, “Ubuntu” 538). Such a supposition is reflected in Esmail’s narrative representation of Tatu’s agency. I show how, as the narrative develops, supportive acts of others eventually enable Tatu to step into in a world where she has agency, contrary to Mutani’s depiction of Jasiri who is protected by the squad and therefore he remains dependant on the help of other. This assertion is elaborated in the motif of charity that, as the next discussion reveals, alludes to the greatest task of African fiction: to “expose and attack injustice[s]” encountered by marginalised individuals (Chinua Achebe cited in Kolawole Ogungbesan 45-46).

The current section therefore explores how altruism, represented in Esmail’s *Living in the Shade*, contributes to Tatu’s agency. It establishes whether and how Esmail’s depiction of humanitarian agendas “compensate for the deprivation and violence” to which one is subjected and might therefore guide victims in their quest for agency (Sabsay 180-181). To support this point, I argue that Esmail signifies the characters of Sister Julianne, Brother Karimu and Mama Mkubwa, among others, as individuals who advocate for an inclusive society. As I will show, one can conceive of these characters as empowering representations of physical presences in children’s literature which might “significantly revise[...] conservative narratives”, like those

which configure children born different as powerless, disabled, or sub-human (Barker 28). Through their efforts, Tatu emerges as an agent among other learners and in the neighbourhood.

In *Living in the Shade*, Tatu's social acceptance and her subsequent capacity to exercise agency are partly activated through her encounter with other informed characters, like Sister Julianne and Brother Karimu, who evoke humanitarian responses and contributions. Their importance is expressed in Tatu's reflection: "God had sent us help through these wonderful people" (36). This rhetoric signals how interventions by these altruistic characters into Tatu's life might ameliorate her ordeals. Their interventions react to the situation in which Tatu considered herself unlucky or cursed because she lacked friends who could care, help, and support her during her encounters with prejudiced people. Two altruistic characters who might bring Tatu hope are introduced as follows:

When I got up this morning, I thought it would be like any other day. Little did I know that today was not going to be an ordinary day. It would be a day that would change my life forever. It would change my attitude, my dreams, and the way I think. Today was the day we would have two special guests in our class. (16)

The event foreshadowed in this retrospective telling, with its optimistic tone, marks a shift in Tatu's positioning as subject and the transformation which positively affects her agency. In the course of the narrative, although the passage does not specifically name those whom Tatu identifies as "two special guests", we learn of her encounter with Sister Julianne, a woman who "had the same skin condition as [hers]" (23), and Brother Karimu. They are "special guests" at Tatu's school and eventually they become her friends and supporters. Introducing Brother Karimu and Sister Julianne as the representatives of a local NGO, Esmail imagines these characters as fulfilling roles which directly respond to Tatu's entreaties and would result in financial contributions, which would help to limit the constraints to her agency and wellbeing.

Brother Karimu and Sister Julianne's positive influence starts when they arm Tatu with more knowledge about her condition; this positive view is further developed when they educate the community on albinism. Soon after Tatu met them at school, the two NGO representatives visit Tatu and Mother at home. On this occasion, Sister Julianne's explanations on the condition of albinism enable Tatu to understand: "I had a [genetic] condition called albinism" (25). Such awareness is preceded by another act of kindness, when Brother Karimu and Sister Julianne provide her with a parcel "full of goodies [...] long-sleeved T-shirts, a cap, a bottle of sun-blocking cream and a pair of sunglasses" (23). This parcel, not given to the other children, signals Brother Karimu and Sister Julianne's NGO's attempts to improve Tatu's living

conditions. The narrative explains that some of these things “will help to protect” Tatu’s “skin from the sun” (23). Through this incident, the narrative orchestrates the role of NGOs as enabling Tatu’s mobility. The protective gear would allow her comfortably to navigate the world around her without being exposed to the damaging sun. Because children’s literature “best” “transmits” the “cultural heritage” (Osa 45), such as *ubuntu* morals, like Brother Karimu and Sister Julianne’s compassion, provides child readers with a lesson about kindness and fair treatment of those with albinism.

Protective gear is not the only benefit Tatu receives from Brother Karimu and Sister Julianne. These characters’ treatment of Tatu reflects what the African philosopher, Kwasi Wiredu, describes as *ubuntu* “moral practices”: the “consideration and enhancement of human well-being [...] dignity, respect” and appreciation of people irrespective of who they are (quoted in More 7). For Tatu, Brother Karimu and Sister Julianne are but “friends who understood [her] and liked [her] for who [she was]” (25). These characters are friendly, tolerant, and accommodating of human difference. With such *ubuntu* qualities, they reinvigorate Tatu’s confidence and self-acceptance. They also promise to change her bitter experiences at school, saying: “everything would be alright” (25). This promise extends beyond the immediate and physical to suggest that they will accord Tatu what Butler would name “protection from injury [...] destruction” and “inequality” (“Rethinking Vulnerability” 15). Their care hence denotes an initial moment where, in the public space, people would no longer mock Tatu for having a genetic condition, but rather that her personality is accepted and embraced.

As it is suggested, Brother Karimu and Sister Julianne have unconditional love for humanity. They do not stand for the injustices that Tatu has had to endure. Their consideration of Tatu reminds us of the view that one’s full humanity depends on whether one “constitutes part of a social order” (More 157). This interpretation is supported by these characters’ efforts, “a new aim” to “create awareness on albinism, as there was such a great misunderstanding about this condition” (37). Here, Esmail’s representation reflects the campaigns of local NGOs, such as the Tanzania Albino Society (TAS), whose workers embody Garland-Thomson’s conception of a “minority rights movement” which seeks to reintegrate those marginalised by society (“Misfit” 597), like Tatu. This role is further implied when Esmail mentions other altruistic roles of the NGO: “to prevent children abuse” and “promote education for children throughout Tanzania” (23). With these characters, Esmail’s novella performs that which is characteristic of the best African writers: to “help the [people in the societies regain] belief in [themselves] and put away [...] denigration and self-abasement” (Achebe 44). The novella seems to seek to empower disenfranchised people, including children with albinism.

Through the characters of Sister Julianne and Bother Karimu, the child reader might learn that despite her albinism, Tatu should be treated as per *ubuntu* virtues — being treated by others with “justice and fairness” (Letseka, “In Defence” 48). Such a lesson reinforces Yenike-Agbaw’s supposition that, as children read stories, they revise their “‘past experiences’ or the ‘knowledge of the world’” (447). This interpretation seems valid because the NGO had “[c]onduct[ed] intensive workshops in [Tatu’s school and] neighbourhoods” and “people now understood about [Tatu’s condition and have] accepted it” (52). This turn of events responds to one of Tatu’s entreaties, in which she longed for an environment where her difference would be accepted. Once one’s difference is accepted, he/she is granted “[a]ccess to civil and human rights” (Garland-Thomson, “Misfit” 601) — the exercise of agency through social exchange and mobility.

Therefore, in her portrayal of Sister Julianne and Bother Karimu’s interventions, Esmail envisages a society in which the character with albinism, to cite Butler, would stand as an “embodied subject who exercises speech or moves through public space, across borders,” and is “free to speak and move without threat” of being injured (“Rethinking Vulnerability” 14). The awareness the two above-mentioned characters created regarding albinism eventually dismantled the negative and discriminating attitudes that Mrs Pili and other learners held against Tatu and albinism generally. The beliefs that a child with albinism is “cursed” and “brings bad luck to [others]” has been neutralised (33) and the learners who stigmatise children with albinism by saying that they have germs or diseases that can infect them, have been silenced (33). Consequently, “Neema, and a few other girls” have accepted Tatu as their friend. They even “gesture [...] for [her] to join them” (42). This change gives her agency to finally fulfil the desire to ‘hang around’ with Grace and Neema, a point well conveyed by an illustration (figure 4). Tatu is no longer excluded by potential friends, rather she is amongst her peers, the very thing that gives her strength as symbolised by the lion, a point to which I return in paragraphs to come.



**Figure 3: Tatu with friends**

The socially mediated agency achieved through Sister Julianne and Brother Karimu's intervention, recalls Susan Dodds' assertion that good carers, on whom "young children" depend, may assist marginalised children to become agents of their selves (185). Therefore, because "much of children's literature ... is created to ... educate" children (Achufusi 172) about altruism, Esmail's narrative seem to remind her readers that a "person with ubuntu is open and available to others, affirming of others [...and] is diminished when others are humiliated or diminished, when others are tortured or oppressed, or treated as if they were less than who they are" (Tutu 34). The story thus may instil the moral of founding a hospitable community in which children, irrespective of their particularities, are accommodated — hence the achievement of equality, as opposed to Mutani's kind of altruism, which constructs dark-skinned children in a manner that frames albinism as a deviance.

Moreover, in "conduct[ing] a workshop with all the teachers in Tatu's school" (37), Karimu and Julianne have managed to change the teachers' perception of Tatu and albinism. Now, Mrs Pili is "genuinely a changed person" (38): she "had stopped being mean to" Tatu and "had asked" her "to move and sit in the front row" (38). Consequently, Tatu is no longer a non-participant during the lessons in class. She gives her "opinion and hear[s] opinions of others" (52). Exercising such agency, she says: "I [feel] like any other children in the class. It [is] really great to be accepted" (52). Here, her words indicate an increased level of agency and her dream of becoming a teacher, which, as I said, signalled her desire for independence, which now seems feasible. As per *ubuntu*, Tatu is now part of her school community. Quoting Garland-Thomson, I would argue that Sister Julianne and Brother Karimu have "work[ed] toward building a sustainable environment that offers fits where misfits have occurred" ("Misfit" 600-601). As a result of these characters' intervention, Tatu earns social agency. She becomes part of the group of learners — an actor among them.

Nevertheless, Esmail's depiction of the NGO's altruistic efforts, which brings changes in Tatu's social life and personality, is complemented by the moral support she receives from other caring characters, such as Mama Mkubwa. This character's caring concern is signified in her interaction with Tatu. Mama Mkubwa cherishes Tatu and motivates her to act as an agent of the self. For example, Tatu's family is isolated by the entire community because of the belief that Tatu is "curse[d] and will [infect] them" (33). Even so, Mama Mkubwa has always been close to Tatu's family. Her behaviour manifests some principles of *ubuntu* — being available to those in need and showing "concern for human flourishing" (Banda 206). As the only good neighbour, when Mama Mkubwa talks to Tatu, she always refers to folkloric elements and positive proverbs to cherish, comfort, and encourage the girl to have faith in herself. One of the

folkloric tales Mama Mkubwa relays to Tatu is of a legendary Maasai warrior and a lion. This is a well-known educational tale in East Africa that teaches Maasai youths how to become warriors. According to Mama Mkubwa's story, when Maasai youths meet "a lion face-to-face" they "stare ... in his eyes. And the lion's strength and courage" will pass into them "through the eyes" (45). Mama Mkubwa narrates this story as a way of encouraging Tatu to cope with the challenges and hurtful circumstances that she faces. She ends the narrative by reminding Tatu: "if you ever meet a lion, remember to stare into its eyes and let its strength pass on to you" (45). The moral of this story gestures towards future events in Tatu's narrative, offering a story that effectively demonstrates how positive intervention has impacted Tatu's sense of agency. It has strengthened her character, self-confidence, and self-sufficiency. For example, when Brother Karimu and Sister Julianne take Tatu and other learners on a visit to the zoo, Tatu sees a real lion, "stare[s] at the lion" and proclaims: "I wanted it to pass its strength onto me so that I could fight the evil in this world" (see figure 4 above — 45). Later, Tatu remarks: "I had trapped its strength with my eyes", and when she slept that evening, she "dreamt the lion smiled at [her]" and "had accepted [her] as a powerful being like itself" (47). The event foreshadowed by this legend suggests that Tatu has developed self-efficacy and the capacity to act for herself, to fight against the ills of the world. Here, Esmail implies that myths and stories, which are means of socialisation in Africa, can be influential on many levels — just as the myths and superstitions concerning albinism can undermine PWA, so stories and myths can also empower them. For example, soon after Tatu's encounter with the lion and her proclamation that she could now confront evils, she is abducted by Juma and his friend. Unlike Jasiri in Mutani's narrative, she manages all by herself to escape. Mama Mkubwa's kindness and her storytelling, as well as Karimu and Julianne's interventions, have strengthened her personal agency, making her aware of her capacity to influence the quality of her life. Her telling is revelatory:

I imagined the sadness that Sister Julianne and Brother Karimu would feel at my loss. Was I so weak that I couldn't do anything? What about the strength passed on to me by the lion? The strength of a Maasai warrior. Was I not going to use that strength to protect myself? Was I going to let a witchdoctor kill another innocent being for his benefit? I remembered a proverb: Pain is inevitable. Suffering is optional. I could put a stop to this suffering. I had to try to escape. I could get help. I had to get back home to Mother. Mama Mkubwa's advice crossed my mind, "Ask God for anything, and He will help you". That is exactly what I needed to do. At least this way I would have died trying. I

felt a gush of power flow into my veins. Where did this force come from? Had it always been there, or was it passed on from the thought of the mighty lion? (80-81)

This revelation, in addition to Tatu's next remark, "I wasn't going to despair; I wasn't going to let some dumb person kill me for nothing" (82) mark how Esmail's imagining of the vulnerable child with albinism departs from Mutani's, which associates childhood albinism with passivity or victimhood. Regarding Tatu's bravery in facing her enemies, as envisioned in the passage above, one recalls Gambetti as expressed in her work: "Risking Oneself and One's Identity: Agonism Revisited" where she asks questions regarding vulnerability and agency. In this work, Gambetti asks: "Is there agency in suffering?" (29). Granted, Tatu's courageous personality in the passage implies another one of Gambetti's assertions, namely that "perils are constitutive of the acting self" (33). One then learns that although Tatu is vulnerable, yet she can be active, daring, and agentic in her striving for survival. These characteristics contrast with her initial view of herself as vulnerable, passive, and powerless, unable to act bravely in response to her problems. The reasons behind this shift call for further consideration. Granted, Tatu's agential sense presupposes Dodds' observation that "some kinds of social [...] responses", taken to ameliorate children's vulnerability, "can generate vulnerability, while others can promote resilience, autonomy, and recognition" (182). In the light of Dodds' insight, Esmail's story can be seen as reinforcing one of *ubuntu's* maxims as elaborated by Metz in his study, "Ubuntu as a Moral Theory and Human Rights in South Africa", that "through other persons" one is challenged to develop one's own full personhood (536). Thus, with the help of other persons, one attains the confidence to act and influence one's own life, as Tatu's agential change reveals.

Because of Brother Karimu, Sister Julianne, and Mama Mkubwa's support, Tatu no longer calls for help. She has developed trust in her own efficacy and a belief that she can change things in her life. When she is abducted by Juma and his friend, she speaks and acts in a manner that displays her efficacy. In addition to her resistance: I will not "let some dumb person kill me for nothing" (82), Tatu expresses her strength:

There was still hope. I'd to get out of the boot. I shuffled and tried to quicken my pace. I was determined to untie the knot on my feet. Finally, the knot loosened. I continued to wiggle forcefully. At last, I forced my hands through the rope. I'd done it! I was free. I felt a sense of elation only for a few seconds. I was still in the boot. If they opened it now, I was as good as dead. They'd tie me up again and there would be not enough time to for me to escape. They'd run after me, and there would be no chance of getting away from these men. The quicker I escaped the better, as I would catch them off guard (84).

These comments frame Tatu as a fine example of a child who fights for her own safety and life. She thus achieves self-realisation, she becomes an agent of the self. She appears capable of altering her situation to positively influence her life. Unlike Jasiri in Mutani's story, she is no longer a passive target in her life circumstances or of others' actions. Tatu's depiction invites the consideration on whether Esmail's portrayal of children with albinism "capture[s] the complexity of their experiences as Africans, children, and human beings" (Yenika-Agbow, *Representing* xvii). The suggestion can be affirmed, as one sees that Tatu is a round character, she is complex and has, to use Connie Epsien's expression, "convincing motivation" for her behavioural change and action (quoted in Achufusi 177). Unlike Jasiri, Tatu appears, to me, as a character whom the reader might admire and want to befriend.

Regarding Tatu's agency, Esmail's novella seems to suggest that children with albinism can enact their personhood and exercise agency once they have been freed from social or cultural constraints. Such freedom comes when different, caring actors collaborate to create a sustaining environment that would guarantee children with albinism self-empowerment. Citing Mabogo More, the collaboration in the novella typifies a "communal orientation" of empowerment where "the self is dependent on other selves and is defined through its relationships to other selves" (157). As discussed, it is because of the combined efforts of individual characters and a civil rights organisation that Tatu's story ends with her emerging as an agent of the self, one who contributes to her society and who now fights for the wellbeing of other people with albinism as well. For example, she writes and reads her poem in a public space to educate the audience, to emphasise equality for all — regardless of impairment or disease. One part of the poem reads:

*We need to be loved and cared for*

*A human need for all*

*I am different only on the outside*

*The same as anyone of you, inside.*

*Respect me, love me, and care for me,*

*With my poor vision and glass frame*

*After all, God has created us all the same.*

*I need to be protected like a jewel*

*So please, oh please, don't be cruel* (113, original emphasis)

With these words, Tatu resignifies herself as an agent who asserts herself and other individuals like herself, individuals living with albinism, as human, as unique persons and unique selves. She has thus acquired the voice to make claims for the betterment of the circumstances of other children with albinism. She demands that they should be loved, cared for, respected, and protected. These *ubuntu*-like virtues articulate Tatu's desire for an inclusive society where people with albinism would live as humans and not as *zeruzerus*, ghost kids, or freaks (7).

## 2.4 Conclusion

As established earlier, both Mutani and Esmail imagine the child with albinism as overwhelmed by peril, and as a child whose realisation of agency and autonomy depends on other actants. The two authors advance their philanthropic agendas by creating characters whose actions impact on the agency, personhood, and wellbeing of their respective child characters with albinism. However, there are important differences in the ways in which the altruistic characters in the respective novels act in their efforts to help the child characters with albinism to achieve agency. In Mutani's narrative, the child with albinism is saved and protected by the figure deemed altruistic. However, the relationship between the rescuer, Joan, and the rescued figure, Jasiri, is one which exacerbates the dependence of the latter. Joan exercises a dominant position and frames Jasiri as always incapable of acting on his own behalf. In contrast, Esmail's altruistic characters (Karimu, Julianne, Mama Mkubwa) seem to reinvigorate Tatu, the character with albinism, to act as an agent of the self. They support Tatu socially, materially, and morally and motivate the girl, initially depicted as lacking agency, to act in her own behalf.

Lastly, I recall Grace Ify Achufusi's previously cited assertion that children's literature is "generally" meant "to educate" the child readers in order to argue that, despite their questionable representational aspects (as demonstrated above) Mutani's and Esmail's narratives aim to create awareness of the condition of albinism. It is important to note that, to the young mind (who might take fictional representation as facts) these texts may communicate conflicting ways of seeing albinism and understanding the identity of children with albinism. The writer of children's fiction is therefore ethically compelled to consider the nuances of portrayal regarding its potential effect on child readers. Narratives such as Mutani's run the danger of affirming stereotypes that demean the humanity of children with albinism. His characterisation of Jasiri may imply that albinism is debilitating and that all children with albinism are overly dependent on others, unable to act agentic and, therefore, still different from children deemed normal. Portrayals such as Esmail's, may educate the child reader to recognize that a child with albinism is like any other child. This said, both narratives discussed here

themselves contain much needed incentives to draw attention to albinism and to the care that children need at all times.

## CHAPTER THREE

### INTERTEXTUALITY AND AGENCY: CHARACTERS WITH ALBINISM IN GAPPAH'S AND MAGUBENI'S NOVELS

#### 3.1 Introduction

In the previous chapter, I examined children literature; two narratives, set in Tanzania. The focus was to establish how authors of those texts deploy altruism to depict agency of characters with albinism. Likewise, the current chapter focuses on examining agency in two novels for mature readers which narrate the experiences of female characters with albinism: Petina Gappah's *The Book of Memory* (2015) and Unathi Magubeni's *Nwelezelanga: The Star Child* (2016). The two novels are set in Zimbabwe and South Africa respectively. There are other narratives on the topic of albinism by southern African writers such as Jenny Robson's *Because Pula Means Rain* (2010), and Meg Vandermerwe's *Zebra Crossing* (2013)<sup>15</sup> but I chose to focus on Gappah's and Magubeni's texts over others<sup>16</sup> for they are crucially rich in methods and modes of narration that draw attention to issues of agency. The two novels have thematic and stylistic similarities in their representations of agency of characters with albinism. Both writers position a female protagonist with albinism and the condition of albinism as the focus of their narrations, and they employ cultural and historical intertextual elements to represent their respective protagonists' experiences of living with albinism. For example, Gappah's narrative interweaves elements from Shona folklore, classical Greek mythology, Ethiopian Orthodox beliefs, and a scope of additional narratives to represent how an array of historical and contemporary perspectives shaped, and continue to shape, ideas of albinism, and therefore impact on the experience of Memory, the female protagonist with albinism, who is incarcerated in Chikurubi Prison for the murder of Lloyd Hendricks. Equally, Magubeni draws on spiritual and mythical elements, especially from Xhosa folklore, to represent Nwelezelanga's story of her spiritual journey as a divine messenger who lacks recognition and respect because of her condition, albinism. In this chapter I explore how intertextual elements in these narratives function to suggest agency, and issues related to albinism.

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<sup>15</sup> Meg Vandermerwe's arresting debut novel recounts the story of a young Zimbabwean girl, Chipso and the difficulties she faces as an illegal immigrant in South Africa and as a person with albinism. Jenny Robson's youth novel is about a young Tswana boy with albinism who lives in Botswana. While both novels are similarly rich in techniques of representation, I selected only one text by a South African writer for examination in this chapter.

<sup>16</sup> As I was heading towards the closure of this thesis, I read Rutendo Tavangerwei's *The Colours That Blind* (2019). Tavangerwei's fascinating novel is set in Zimbabwe and depicts the experiences of a thirteen-year-old boy, Tumirai, socially ostracised because of his albinism. I aim to study this narrative in future research.

By agency I refer to Maria Pia Lara's description in her book *Moral Textures: Feminist Narratives in the Public Sphere* (1998) suggesting that narratives have the ability "to perform new meanings" on those it presents and speaks to (*Moral Textures* 44), because

[a]s agents of cultural contact, narratives work across the boundaries of their own culture, as well as of those cultures that incorporate them. They engage public opinion in a continual process of dissolving, reshaping, expanding or transgressing boundaries that have been drawn at various levels of cultural socialization. (*Moral Textures* 152)

Here, Lara talks about the narratives' capacity to bring transformation within their own traditions as well as beyond them. Echoing this assertion, I intend to establish whether intertexts destabilise some entrenched assumptions about albinism as represented in the two novels. An important point to note is that when narratives that speak for the marginalised enter into the public sphere, they become a means through which these individuals can act to reconfigure justice. Lara elaborates on this as she writes on the force or power that narratives have among the reading public. According to Lara, as "emancipatory narratives" enter the public, they "mediate between particular group identities and universalistic moral claims, providing new frameworks that allow those who are not members of the group to expand their own-self conceptions and their definitions of civil society" (Lara 3). Lara's ideas are crucial in the argument advanced in this chapter, and I wish to complement her thoughts on agency (as a process of resignification) by deploying Judith Butler's idea of "performative agency" ("Performative" 185). According to Butler, the term implies incidents where an "utterance or practice" is capable of "bring[ing] that of which it speaks" into being ("Performative" 185). I thus consider Lara as well as Butler, and use "agency" to infer the capacity of an agent or a text to (re)define ontological and perceived truths about albinism and PWA. Lara's and Butler's arguments thus inform my approach through which I examine how intertextual insertions in the novels signify speech acts capable of "counter[ing] certain metaphysical presumption[s]" of albinism as a "culturally constructed category and to draw our attention to the diverse mechanisms of that construction" (Butler, "Performative" 147). I consider whether these intertexts have the agentic capacity to transform "certain kinds of realities" (Butler, "Performative" 147) concerning PWA. I will elaborate more on these scholars' ideas in the section, "Literary Overview and Theoretical Framework", where I define and extrapolate on the theoretical premise that guides my reading of agency and the role of intertextuality in this chapter. I broadly use intertextuality to mean the practice in which a writer of a text makes references to elements of existing art and narratives and/or other forms of cultural production

to draw attention to the complexity of their thematic concerns (Allen 1, 4, 5), notably in relation to albinism.

This chapter explores how multi-layered intertexts limn perceptions of albinism within the socio-cultural (historical) contexts in which the respective stories are set. As per concern of this dissertation, the chapter examines how intertexts in the studied novels allow their respective narrators agency to configure, endorse or distort pre-established oppressive discourses circumscribing PWA. I argue that, as a narrative technique, intertextuality permits the reader an understanding of the experiences of characters with albinism. The technique informs the reader of the complex network of narratives and beliefs that have shaped and continue to shape the experiences of people with albinism in the real world. In the section: “Literary Overview and Theoretical Framework”, I demonstrate that both novels have received critical attention regarding matters of agency, but existing criticisms do not focus extensively on intertextual insertions and how these signify illocutionary or performative agency. Thus, the chapter examines the effectiveness of intertextual insertions to represent impediments and possibilities for personal and public agency of PWA in the two texts.

### **3. 1. 2 Literary Overview and Theoretical Framework**

This section presents an overview of the critical attention *The Book of Memory* and *Nwelezela: The Star Child* received and explains which aspects of these assessments inform my argument and motivate my inquiry. The section further introduces key theoretical views that guide my interpretation of the novels.

Of the two novels, Gappah’s *The Book of Memory* has received most critical attention. In “(Re)drawing the limits of marginality ‘Whiteness’, disability and queer sexuality in Petina Gappah’s *The Book of Memory*” (2015), Gibson Ncube and Asante Lucy Mtenje explore how marginalised characters such as Memory (with albinism) and Lloyd, a gay man, are brought together by respective experiences of discrimination. Ncube and Mtenje argue that Gappah’s narrative depicts “the marginalised body as one capable of agency and existence in its own right” (1). I pursue this line of inquiry but focus on how narrative and cultural elements (intertexts) are reworked in Gappah’s novel to limn the narrator’s performative agency. I further consider whether such agency counteracts or affirms terms that socially subordinate PWA and their female acquaintances or relations.

Ken Junior Lipenga and Emmanuel Ngwira, in (their earlier cited study) “‘Black on the inside’: albino subjectivity in the African novel” (2018), “examine ways in which characters with albinism have been” afforded forms of agency (1474). Their study assesses five Southern

African novels, including Gappah's *The Book of Memory* and Magubeni's *Nwelezelanga: The Star Child*. Lipenga and Ngwira propose that in fiction, agency is bestowed on characters with albinism through "the acqui[sition] of voice; the explicit presentation of the experiential side of the albino's life; and the articulation of basic human emotions" (1475-1476). Their arguments are informative, but they do not fully explore agency in terms of intertextual insertions in Gappah's novel, although they comment on the significance of magical powers in Magubeni's text. I develop my investigation to discuss how elements of embedded narratives imbue characters, such as Nwelezelanga, in Magubeni's novel, agency to evoke positive reader appreciation. These critics concentrate on how fantastical properties of Magubeni's central character frame her as a devil incarnate, thereby dehumanising albinism (1482). I aim to build on this assertion, and to demonstrate whether intertextuality affords Magubeni's and Gappah's narrators illocutionary/performative agency to reverse the dehumanisation of the protagonist and, by implication, other PWA. My reading intends to closely explore Magubeni's and Gappah's use of intertextuality and to add to Lipenga's and Ngwira's critical interpretation of these texts.

In "Writing in and about Prison, Childhood Albinism and Human Temporality in *The Book of Memory*", Isaac Ndlovu examines Gappah's "construction of human time or temporality through narrative" (35). Commenting on how Gappah's account invites comparison to Sophocles' story of Oedipus Rex and the logic of *ngozi*<sup>17</sup>, Ndlovu regards the logic of *ngozi* as Gappah's way of suggesting the lack of a promising future for her protagonist with albinism, Memory, who is bound by physical imprisonment. He further interprets the inclusion of the legend of Oedipus as a technique through which Lloyd, the character who lectures on Oedipus, "authors his own tragic death and propels Memory into a tragic future" (41). I wish to add to this conversation in my investigation of how intertextual elements, myths, and beliefs function to foreground Memory's future or undermine her agency. Further investigating ideas from Ndlovu's study, I aim to fully explore how Gappah's intertextual insertions, from different cultures, provides her narrator with the agency to affirm or resist demeaning social cultural terms and beliefs that disregard empowerment of PWA. I further ascertain whether Gappah's inclusion of these intertextual elements humanises PWA or whether it sustains perceptions of albinism as a curse, predetermining suffering to individuals with albinism and their parents.

Building on ideas expressed in the studies reviewed above, this chapter adopts the notion of intertextuality as critical lens to trace and describe what Graham Allen would describe, in

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<sup>17</sup> I will unpack this logic in the analytical section

*Intertextuality: The New Critical Idiom* (2000), as effects of “explicit and implicit relations that a [text has to other prior texts]” (87) and to consider how such relations function to designate aspects of agency in relation to perceptions and experiences of characters with albinism. One of the key figures who theorises intertextuality is the French philosopher, Julia Kristeva. In *Desire in Language: A Semiotic Approach to Literature and Art* (1980), Kristeva uses the term intertextuality to transform semiotic criticism (popularly associated with Ferdinand de Saussure, Roland Barthes and even Kristeva herself) in which the meaning of a text must be generated from its internal signs and system. Such criticism was thought to be insufficient because one is only “involved in a signifying process [isolating a text from] its everyday function as an instrument of simple communication” (Roudiez, “Introduction”, in *Desire* 3). Intertextuality, defined by Kristeva, is when “the space of a given text” includes “several utterances, taken from other texts” which “intersect and neutralize one another” (*Desire* 36). Henceforth, she continues, “any text is constructed as a mosaic of quotations; any text is the absorption and transformation of another” (*Desire* 66). Implied here is that the new text affords the merged texts with a space and the capacity to act upon each other and to affect the meaning and performances of all texts involved. The novels I study are no exception, as I will demonstrate in reference to pre-existing written/oral texts, a practice commonly used by African novelists, also showing how these enable each writer to constitute the meaning of their works (Ogede 3). In so doing, these texts (re)articulate various experiences and perspectives regarding their respective narrators with albinism while affording them agentive utterances to subvert and/or affirm social marginality of PWA.

Kristeva’s theorisations of intertextuality draw mostly from Mikhail Bakhtin’s idea as expressed in his often-cited work: *The Dialogic Imagination: Four Essays* (1981). In this book, Bakhtin clarifies (and I agree) that a novel “represents all [significant] social and ideological voices of its era” (411). I regard the intertexts included in the novels as textual signifiers embodying varied ideas and voices. To examine how these voices and ideas are essential in revealing differing perspectives on albinism, and to establish whether these perspectives are agential enough to revise negative experiences and offensive terms circumscribing PWA, I turn to Bakhtin’s arguments. Bakhtin writes:

Directed toward its object, a word enters a dialogically agitated and tense environment of alien words, evaluations and accents, is woven into their complex interrelationships, merges with some, recoils from others, intersects with yet a third group: and all this may in an essential manner shape the word, may leave a trace in all its semantic

layers, may complicate its expression and influence its entire stylistic. (*The Dialogic* 276)

Guided by Kristeva's and Bakhtin's assertions, I read the selected novels to ascertain whether literary and cultural elements alluded to in Gappah's and Magubeni's texts nurture agency for their respective narrators to redefine images of PWA. I consider how agency, imbued in the intertextual materials, humanises the characters with albinism, contests their social subordination or affirms prejudices/narratives that question their humanity.

I further utilise Ato Quayson's notion of "aesthetic nervousness" (*Aesthetic Nervousness* 15), and his idea that art may refract reality (*Aesthetic Nervousness* 15), to interpret whether the depiction of a character with albinism implicitly and explicitly alluded to in texts condones or refracts the reality of PWA who are stigmatised and alienated. In his previously cited book: *Aesthetic Nervousness: Disability and the Crisis of Representation*, Quayson writes of "aesthetic nervousness", the term he uses to refer to representational crises associated with a disabled figure. Quayson claims:

In works where disability plays a prominent role, the reader's perspective is also affected by the short-circuiting of the dominant protocols governing the text – a short-circuit triggered by the representation of disability. For the reader, aesthetic nervousness overlaps social attitudes to disability that themselves often remain unexamined in their prejudices and biases. (*Aesthetic Nervousness* 15)

Here, Quayson implies that a text generates aesthetic nervousness when it represents a disabled body as exceeding the prevailing conventions of fictional representation in a manner that does not challenge the social constructions of a disabled body. Quayson adds that such anxiety can extend to "tensions refracted across other levels of the text such as the disposition of symbols and motifs, the overall narrative or dramatic perspective [...] and so on" (*Aesthetic Nervousness* 15). While characters with albinism in the studied texts are not necessarily represented as disabled, albinism is presumably regarded as a disability in the regions where the two texts I explore are set. I employ Quayson's ideas to examine whether the narratives I analyse represent albinism in ways that ignore, or bypass prejudices and biases associated with albinism. Hence, I consider whether intertexts are agentive in producing refractions in the representation of characters with albinism. I try to ascertain whether intertexts might rectify damaged images of characters with albinism, "[p]lacing them in a condition of ordinary everyday interaction [or evict them] from the dominant modality of merely occasioning virtue (either negatively or positively) to being fully acknowledged persons in themselves [in relation to] how others

perceive them in the world” (Quayson, *Calibrations* 121-122). As in the previous chapter, I continue to draw on ideas offered in the field of disability studies by critics such as Tobin Siebers, to complement Quayson’s.

Lastly, to argue whether each narrative constructs or reconstructs issues of agency for the character with albinism and the condition of albinism by endowing a specific character with forms of recognition, I continue, as noted, to call upon Lara’s notion of the “illocutionary force”, as discussed in her *Moral Textures*. I deploy this term to ascertain whether intertexts afford the narratives studied with “forms of power [or ...] new ways to fight back against past and present injustices, thus making [...] transformations possible” (5). Lara’s conceptualisation of illocutionary force is employed in conjunction with Butler’s thinking on performative agency (discussed earlier). I use these approaches to determine whether intertexts afford the inquired novels’ respective protagonists with the capacity to subvert monolithic conceptions of albinism in relation to human identities and thereby provoking readers to perceive albinism differently. I aim to demonstrate that some of the intertextual elements in the novels I study carry in themselves what Lara calls “disclosive possibilities”, the ability of narrative to offer a fresh look on things that were once perceived differently (5) and, in this way, I consider whether the writers represent the narrator of each studied novel as agents capable of transforming their social subordination.

In the analytical section of this chapter, I first introduce Gappah’s text and comment on how she refers to her own agenda (as writer and lawyer) to signify her literary advocacy for albinism. Thereafter, I examine how her narrative incorporates elements from Ethiopian Orthodox texts and from Shona narratives to (re)articulate historical perceptions of the origins of albinism and to consider whether those views or utterances afford the narrator (Memory) agency to resist or endorse the dehumanisation and the stereotypes associated with albinism. Such stereotypes include how giving birth to children with albinism and albinism are framed as a curse. I then proceed to explore Gappah’s references to Shona beliefs (*ngozi*) and classical Greek mythology. Here I focus on how naming functions in transforming the experience and to circumscribe the personal agency of Memory. In part two of the analytical section, I analyse Magubeni’s novel and focus on how the deployment of Xhosa folklore, especially allusions to the logic of reincarnation, the tale of creation, as well as mythical and spiritual figures, influence readers’ perceptions of albinism. I consider whether, in the use of these textualities, Magubeni depicts his character with albinism contrary to preestablished imaginings regarding the condition.

Magubeni is a *sangoma*,<sup>18</sup> therefore it is of interest to comment on how his use of folkloric material interprets and reinvents the ways albinism is perceived by traditional healers.

### 3.2 Petina Gappah's Writings: Advocacy for the Marginalised

As I mentioned, although *The Book of Memory* is Petina Gappah's debut novel, at the time of its publication, Gappah had already established a reputation as one of Africa's emerging contemporary fiction writers. She had already received praise for her short story collection *An Elegy for Easterly*<sup>19</sup> (2009) which was nominated for various literary awards. Gappah has since published another collection of short stories, *Rotten Row* (2016) and a novel, *Out of Darkness, Shining Light* (2019). Like the *Book of Memory*, Gappah's short story collections and her recent novels are concerned with representations of the marginalised. Gappah is a qualified lawyer who obtained her first law degree at the University of Zimbabwe and then studied International Law at Cambridge University.<sup>20</sup> She has a doctorate degree "in International Trade Law from the University of Graz in Austria".<sup>21</sup> Literary creativity is thus another platform that Gappah uses to advocate human rights; a theme that underpins her fiction, including *The Book of Memory*.

*The Book of Memory*, as its title suggests, presents the memories and experiences of the first-person narrator and protagonist, Memory — also referred to as Mnemosyne (2).<sup>22</sup> As I have clarified, Memory is a woman with albinism. She is in her twenties and is incarcerated at Chikurubi Prison, Harare, Zimbabwe, waiting to be hanged for a murder she had not committed — the murder of Lloyd Hendricks, her adopted father; a wealthy white man, a university don, who had taught classical literature, and who has translated the story of Oedipus into Shona.

As she makes it clear from the outset, Memory tells her story and writes it down for Vernah, a lawyer, who wants to use the testimony to defend Memory's case in court. Vernah hopes that if Memory "record[s] everything that could make her case sympathetic" (8), the testimony would serve to overturn the death penalty Memory has received (35). The second recipient and reader of Memory's story is Melinda Carter, an American journalist who has "made a career out of exposing miscarriages of justice" (9), and who in this regard will voice her appeal to the

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<sup>18</sup> A traditional healer (in southern Africa). *Sangomas* are accused of propelling the belief that body parts of PWA have magical spells. *Sangomas* (are popularly known as *waganga wa kienyeji* (in Kiswahili) in East Africa (especially in Kenya and Tanzania). The *waganga wa kienyeji* like their counterparts *Sangomas* are also accused to spread this deadly belief regarding magical and spiritual power of body parts of people with albinism.

<sup>19</sup>The winners of *The Guardian First Book Prize* in 2009 <https://www.irishtimes.com/culture/books/review-the-book-of-memory-by-petina-gappah-1.2376101>

<sup>20</sup> See <http://www.womeninforeignpolicy.org/law/petina-gappah-international-trade-lawyer-zimbabwe>

<sup>21</sup> See <http://www.womeninforeignpolicy.org/law/petina-gappah-international-trade-lawyer-zimbabwe>

<sup>22</sup> The term re the Greek goddess of memory. See <https://www.britannica.com/topic/Mnemosyne>

public. With both a lawyer and a writer serving as listeners, hearing, and reading Memory's testimony, Gappah alludes to her own personal investment in the thematic concerns of her tale, as lawyer and creative writer. This is a point on which she comments in an interview about *Women in Foreign Policy*. She notes: "Storytelling humanises even the most difficult situations of conflict".<sup>23</sup> Thus, her feminist agenda is underscored by the casting of three female characters as mouthpieces of her human rights tale.

Relaying her autobiographical multi-layered first-person account of the complicated events that brought her to Chikurubi Prison, Memory is granted two forms of narrative agency. She is endowed with the power to narrate or *tell* and to write her story using a non-linear plotline, but nevertheless one through which readers may establish connections between the different temporal scales of the narrations as they unfold. In doing so, readers gradually become acquainted with her story—it forms an accurate and coherent representation of her claims and the nature of her conviction. Significant to the plurality of her account are her recollections of her relationships with her now deceased parents (Moirra and Benson), her siblings (Joy, Moreblessing and Gift), her childhood neighbour with albinism, Lameck, as well as her encounters with Lloyd's family (such as his sister, Alexandra) and his friends, Zenzo and Allan Milhouse. The reader also learns of Memory's childhood experiences, especially at school, and the lessons taught by the nun, Sister Mary Gabriel.

In my view, the textures of Memory's story recall Lara's claim that women's writings concern themselves with uncovering problems encountered by women and to expose those problems to the public by "provid[ing] an account of the lack of justice created by a situation of marginalisation, oppression or exclusion" (16) for the purpose of reinterpreting their lives. Hence, one can read Memory's reasons for writing her story as a symbolic reflection of how Gappah voices the injustices facing those women who are incapable of speaking for themselves. This role, as I stated earlier, signifies Gappah's undertaking in her own writing as an author and as a trained lawyer whose narrative creatively records the lives of those individuals subjugated, marginalised, and forgotten, for the purpose of giving a new meaning to their experiences.

Gappah's novel, therefore, can be interpreted as supporting the central agenda of African women's writing, for it affords the narrator with a space of performative agency to present the views of African feminist and literary critic, Grace Chinyere Okafor, in "Rewriting Popular Myths of Female Subordination: Selected Stories by Theodora Adimora-Ezeigbo". According to her, one of the roles of African literature about the welfare of marginalised individuals, is to

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<sup>23</sup> (<http://www.womeninforeignpolicy.org/law/petina-gappah-international-trade-lawyer-zimbabwe>).

“attack [...] stereotypes and misconceptions” confounding these individuals (82). Indeed, Gappah’s narrative, as I will demonstrate, seems to reflect Okafor’s argument that through writing, women in Africa expose myths which bring about their subordination, explore their inherited negative stereotypes, while also according themselves positive recognition (82). Indeed, *The Book of Memory*, as the coming sub-section reveals, mediates the acceptance of a woman with albinism in cultural imperatives which tend to render her condition as one that negates PWA’s humanity.

### 3.2.1. Intertexts and Historical Perceptions of the Origins of Albinism

Memory’s promise to tell her readers of her experience of being born and raised with a “condition that makes [her] white but not white and black but not black” (5) corroborates Gappah’s socio-political agenda of thematically exploring albinism and the marginalisation of (female) subjects. This descriptive naming of albinism gestures towards perceptions in pre- and postcolonial Zimbabwean society which reflects a lack of knowledge regarding albinism as a condition. It echoes how people in African contexts have “fail[ed] to see albinism [as] a medical condition” (Baker, “Writing” 91). Such a failure implies that PWA are often perceived in terms that deny them a racial category and humanity.

For example, before Memory became reconciled to her condition, the social contexts regarding albinism made her view herself with self-hatred. She looked upon albinism as demeaning her: albinism, she says, made her look “pale” like a “ghost among others” (3). Here, one notes the narrator’s internalised stigmatisation, which provides her narrative with the mocking tone that is characteristic of her style. She uses that tone to echo society’s disparaging comments about bodily differences and how these comments create fertile ground for the development of self-loathing. The mocking tone thus signifies a “narrative disclosure”, conceptualised by Quayson, in his celebrated text, *Calibrations: Reading for the Social* (2003) as an avenue, “where the disabled figure is allowed to provide the central locus of consciousness in the narrative text, providing a perspective on the doings of others while at the same time actually reflecting upon their disability in relation to how others perceive them in the world” (122). The tone is thus by itself a metaphor of a text signifying the social perception of albinism. Such perception has a negative illocution that declares PWA as non-human, “a ghost among others”.

Furthermore, the narrative disclosure in Memory’s retelling unfolds as she interweaves her lived experiences and the way that her society perceives albinism. Her retelling incorporates different narrative elements from diverse cultural contexts and stories to produce her densely layered account of albinism; one which signals that her story is an agentive utterance capable

of stating and overturning pre-established terms which ostracise people who appear different. In recalling how her society perceived albinism, Memory refers to the Shona children's play, *Mahumbwe* and the legend of Noah and Lamech; characters whose stories are featured in various religious Christian and Ethiopian Orthodox texts. As Memory remembers Lameck, a child with albinism she knew during her childhood on Mharapara Street and exposes her society's distressing perceptions of albinism when she remarks: "What made my situation worse – at least, as I saw it – was that I was not the only albino in the township. The other was Lameck, who had a squashed face and red, blotchy skin that broke over his arm and face. His hair was almost orange" (52-53) and he "looked incomplete, as though he had been fashioned at *Mahumbwe* play [<sup>24</sup>] by a careless child and then been fought over before being abandoned to be stamped on as the children hurried into their suppers" (54). The connotation is clearly that PWA are incomplete beings, compared to people who are considered normal. Due to this perception, Memory "gave [Lameck] no affirmation at all" (53). The reference to *Mahumbwe* play not only conveys a hint of how Gappah's text incorporates an assortment of extracts or an amalgamation of later, revised Shona cultural texts, but also signify how Memory and her society reductively perceive PWA— as incomplete creatures. The referencing invites readers to more multifaceted perceptions of albinism and signifies the available narratives, which question the humanity of PWA. As Wole Soyinka's elaborates in his study, *Myth Literature and the African World* (1976), people born different such as those with albinism, are perceived in Africa as God's imperfect creation (159). This initiates society's denial of albinism as a valid, agentive form of humanity, perpetuating a skewed and selective perception that PWA are inferior. For Memory this view also contributed to her self-othering, as is further evident in her strong desire to have a darker skin colour, because albinism for her means she "was three, possibly four shades away from beauty" (56), a point further emphasised in her admiration of dark-skinned women featured in *Parade* magazine (56).

Before I proceed to demonstrate whether Memory's recollection has the agency, the potential, to "counter the offensive call" (Butler, *Excitable Speech* 2) regarding how Memory and her society disparage albinism, it is valuable to recall the Bakhtinian claim that a text is polyphonic for it includes various voices from different eras and indeed from various cultural contexts. However, these voices, as Kristeva has established, have the agential power to neutralise one another. While Memory recalls how albinism was perceived on Mharapara Street in the

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<sup>24</sup> Children's socio-dramatic play among the Shona through which children imitates adult-like roles  
See <https://folkloreoftheafricanchildrussian13spring2015.wordpress.com/2015/05/31/mahumbwe/>

*Mahumbwe* play, she also draws on the legend of Lamech<sup>25</sup> and Noah to describe Lameck's<sup>26</sup> albinism. As if to counter the prior belittlement of Lameck's physical appearance (albinism) as signified through the *Mahumbwe* play, Memory offers a comparison between the boy's name (Lameck<sup>27</sup>) and that of Lamech, a figure in the biblical story of Noah, which also features in Ethiopian Orthodox texts. She narrates: "I do not imagine that his parents named him after the original Lameck – Lamech, the father of Noah. Sister Mary Gabriel told me that Noah was an albino; that God had chosen to save an albino above all the people he flooded in with wrath" (53). Thus, given the belittlement of Lameck, as noted via the *Mahumbwe* play, Memory's recollection of Sister Mary's quasi-religious<sup>28</sup> story seems to accord her the agency to challenge the cultural script that inhibits the social approval of PWA. Such reference thus defines Memory in relation Lara's theorisation that narratives by women have the potential to alter the way that certain individuals are poorly or negatively conceived (77). The reference further illuminates Okafor's earlier cited assertion that through writing, African women resist the categorisation of those relegated to disdain by their society and that they rework the common myths sidelining marginalised individuals in their narratives (83). Thus, I would say, the intertextual use of the quasi-biblical story has entered a dialogue with the preconceived, polluted connotations of albinism as voiced in other narratives of Memory's socio-cultural context. From such a dialogue, another empowering perception of albinism emerges via Sister Mary's version — albinism is something God created. This narrative intersection reminds us further of another of Bakhtin's views that "[t]he single adequate form for verbally expressing authentic human life is the *open-ended dialogue*" (*The Dialogic* 293). Indeed, the fabricated religious tale referred to in Memory's retelling of Lameck denotes an alternative voice. The agentic ability to resist and rework the negative perceptions regarding the little boy, Lameck, is embedded in this voice and is by implication a factor that counteracts Memory's negative perception of albinism. Furthermore, the shifting or transformation of a negative conception of albinism is even more obvious as Memory relates an extract of a story told by Sister Mary:

*And my son Methuselah took a wife for his son Lameck, and she became pregnant by him and bore a son. And his body was white as snow and red as the blooming of a rose, and the hair of his head and his long locks were white as wool, and his eyes*

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<sup>25</sup> A character in biblical and other religious texts

<sup>26</sup> A fictional character with albinism in Gappah's novel

<sup>27</sup> The spelling is Lamech in various biblical and Jewish or Ethiopian Orthodox sources. The use of Lameck in Gappah's book alludes not only to the biblical story but emphasizes the fabricated aspects of the multi-layered narrative recalled in *The Book of Memory*.

<sup>28</sup> I term this intertext as quasi-religious because the idea that Noah was an "albino" is contested.

*beautiful. And when he opened his eyes, he lighted up the whole house like the sun, and the whole house was very bright. (54 original emphasis)*

The fuller understanding of this form of explicit intertextuality in Gappah's novel recalls Charles Bazerman's argument that an intertextual reading that acknowledges the source of an anterior text, further enriches the understanding of the posterior text because, "[a]nalyzing those connections helps us understand the meaning of the text more deeply" (83). Besides, as Bakhtin puts it, we cannot ignore the impetus of a given text given the ground that "[t]o study the word as such, ignoring the impulse that reaches out beyond it, is just as senseless as to study psychological experience outside the context of real life" (*The Dialogic* 292). As my research reveals, elements of Sister Mary's story, retold above by Memory, resemble the legend of Noah, which is found in *The Book of Enoch*.<sup>29</sup> The resemblance suggests that Gappah drew on the book in her research for her novel. *The Book of Enoch* is an essential text in Ethiopian Orthodox belief and its characters or figures also feature in the Bible,<sup>30</sup> especially in the book of Genesis. *The Book of Enoch*, which is believed to have been dated somewhere between 200 B.C. and A.D. 100<sup>31</sup> traces Noah's genealogy. According to the book, Methuselah is Enoch's son and the father of Lamech, Noah's father. As an intertext featured in the story narrated by Sister Mary to Memory, it describes Noah's hair, eyes and skin colour as resembling those of a PWA. However, despite the semblance, neither the Bible nor *The Book of Enoch* plainly states that Noah had albinism. However, in *The Book of Enoch*, Noah is described, as per the extract above, as having an "unusual" physical appearance and was thought to be a divine figure. His father Lamech believed that he had descended from fallen angels, but Enoch insisted that Noah was Lamech's true son who would save the righteous ones from destruction, and that from Noah, a new generation would spring (*The Book of Enoch* 46-47).

In terms of agency, in Memory's recollection, the legend of Noah features as a further intertext with its own performative agency. Its retelling in Gappah's narrative provides the reader with a context in which the significance of the allusion to a religious figure, Noah, is reinterpreted via Lamech, the character with albinism. Such association of the two rearticulates a positive identity of PWA and authenticates their personhood. This is a clear articulation of the belief

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<sup>29</sup> The extract that Memory cites is also found in *The Book of Enoch*. According to *New World Encyclopedia* "*The Book of Enoch* is an apocryphal and pseudepigraphal collection of second century [Jewish](#) texts attributed to [Enoch](#), the great-grandfather of [Noah](#) ([Genesis 5:18](#)), which describes a group of fallen [angels](#) (called "the [Grigori](#)" -"Watchers") mating with humans to produce a race of giants (called "the [Nephilim](#)") (cf. [Genesis 6:1-2](#))". The source adds that "While the *Book of Enoch* does not form part of the [Canon](#) of Scripture for the larger Christian Churches. Various groups, including the Ethiopian Orthodox Church, regard parts or all of Enoch to be inspired scripture. See [https://www.newworldencyclopedia.org/entry/Book\\_of\\_Enoch](https://www.newworldencyclopedia.org/entry/Book_of_Enoch)

<sup>30</sup> I use Bible to refer to the St James Christian Bible which consists of the Old Testament and New Testament.

<sup>31</sup> [https://www.newworldencyclopedia.org/entry/Book\\_of\\_Enoch](https://www.newworldencyclopedia.org/entry/Book_of_Enoch)

that albinism is an identity created and affirmed by God. We thus see the legend of Noah and Lamech serving as an utterance with the potential to reverse the ill-conceived views of albinism, as signified in the cultural context of the depiction of albinism as retold via the *Mahumbwe* play. Since the legend of Noah is re-narrated by Memory, such retelling makes it seem as though Memory is an agent who resists the view that PWA are “incomplete” human beings or “ghost[s]” (54). It is as though the Ethiopian Orthodox text suggests or declares that albinism and PWA are creations of God. Therefore, since the intersection of texts, as Kristeva and Moi say, involves the “transposition of one (or several) sign-system(s) into another” for “new articulation of the thetic – of enunciative and denotative positionality” (111), then the legend of Noah and Lamech in Gappah’s novel has transposed the Shona’s view of albinism onto a new perception of albinism from Jewish and/or Ethiopic mythological perspectives.

Thus, by including elements from various cultural texts, such as the *Mahumbwe* play, the story of Noah and Lamech, Gappah’s novel unfolds historical, religious, and traditional perceptions of the origins of albinism, and indicates how these tales survive as part of contemporary mythologies and beliefs that affect the lives and social acceptance of PWA, such as in the cases of Memory and Lameck. Additionally, such intertextual insertions afford the narrator, Memory, agentic utterances which redefine albinism and contest pre-established stereotypes which deny PWA their full personhood and humanity. This positive image of albinism and PWA is noted when intertexts metaphorically frame Memory, in her tale, as the agent (and narrator) whose narrative seeks public agency or acceptance for PWA.

In the next sub-section, I continue to focus on Memory’s recollection of her life on Mharapara Street. I consider Gappah’s insertion of motifs from ancient Greek and Shona mythologies into Memory’s account that recalls her experiences in relationships with her family and adopted father, Lloyd. I intend to demonstrate how her recollections draw attention to her perception of herself as a PWA. Furthermore, I explore whether these intertextual stories contribute positively to Memory’s agentic ability to redefine and/or disrupt socio-cultural marginalisation of mothers of children with albinism and PWA within a society, as for example the view that albinism is a sign of divine curse.

### **3.2.2 Naming and Narratives of Fate as Intertexts of Premonitions: Agency and Preordination in *The Book of Memory***

In recalling her experiences, Memory’s tale predominantly features the motifs of death and misfortune. This is when her recollections seem to imply the inevitability of the death penalty, her imprisonment at Chikurubi Prison, as well as incomprehensible deaths of the people in her

social circle. Furthermore, in an incident that imposed imprisonment and the death penalty, Memory is implied as succumbing to fate, lacking free will, with little or no choice, and consequently lacking agency to shape her destiny. The reader thus sees Memory as the protagonist who suffers from the cruelties of fate. Such a plotline seems to affirm the preordained belief that Memory's family and she herself are predestined to suffer doom and despair and her birth (as a child with albinism) is part of such preordination. To demonstrate this view, I examine how Gappah alludes to mythical Greek characters and elements of Shona myths and narratives to represent fate, misfortunes and deaths that pursue Memory and her mother, Moira.

I consider whether these elements allow Memory's narrative agency to sustain or challenge the moral etiological perception of albinism and PWA. For example, giving birth to a child with albinism is thought to be a spiritual retribution. This is a common stereotype haunting PWA in Africa. For example, in "Albinism, stigma, subjectivity and global-local discourses in Tanzania", the German cultural anthropologist, Brocco reminds us that the condition of albinism is "defined as a curse" and/or divine payback (240). Such is not only the case in Tanzania, but also a reality in several parts of sub-Saharan Africa. However, the most important thing to note is that these views mean that women who give birth to children with albinism, as well as those children, are thought of as being infected and are sources of misfortune of some sort. They must be isolated from the society (Baker et al. "Myth" 174). In Memory's retelling, this perception is echoed when Gappah incorporates beliefs, themes, and names of mythical characters figured in written and oral texts to represent experiences of her protagonist, Memory and her mother, Moira.

In the subsequent paragraphs, I examine Gappah's intertextual insertions of aspects from ancient Greek mythology, figured by naming the mother Moira, after the Greek goddesses of Fate (Moirai),<sup>32</sup> and the explicit reference to Sophocles' tragic hero, Oedipus. I also explore the reference to the Shona's spiritual concept of *ngozi* (the Shona's way of pursuing justice in which perpetrators of immoralities, such as murderers, are avenged by a vengeful spirit).<sup>33</sup> These tropes in Gappah's narrative, I argue, complement one another, and draw attention to myths which have influenced cultural perceptions of albinism for centuries, for example, that albinism is the result of a godly or ancestral punishment or curse. They also frame PWA and their

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<sup>32</sup> The Fates –Moirai/Moirae – "are a group of three weaving goddesses [Clotho, Lanchesis and Atropos] who assign individual destinies to mortals at birth".

([https://www.greekmythology.com/Other\\_Gods/The\\_Fates/the\\_fates.html](https://www.greekmythology.com/Other_Gods/The_Fates/the_fates.html)).

<sup>33</sup> Musanga, Terrence. "Ngozi" (Avenging Spirit), Zimbabwean Transnational Migration, and Restorative Justice in Brian Chikwava's *Harare North* (2009)

mothers as figures driven by the cruelty of fate, who have little or no agency to challenge their damnation. Specifically, I demonstrate that there is a resemblance in the behaviour of Moira, Gappah's character and the Moirai (also Moirae/Moira), the Fates in Greek mythology, and that such semblance signifies the performative agency with which Memory's recollection is implied as though it affirms Memory, Moira's daughter with albinism, as the carrier, "spinner"<sup>34</sup> of her mother's fate and curse or that giving birth to a child with albinism is the manifestation of her mother's spiritual torment. Finally, I establish the link between the notion of *ngozi*, the name Moira, and the story of Oedipus as significant to unfold social imaginings of marginalised figures and corporeal differences as 'damned' figures. I consider whether and how the performative agency wrought by these intertexts reinforces or debunks the preestablished narrative of albinism and characters with albinism as being afflicted by a curse and condemned to doom.

Gappah's reworking of the Shona notion of *ngozi*, and of classical Greek literary and mythical tropes, resonates with the claim advanced by the African literary and cultural scholar, James Tar Tsaaior's, in *African Literature and the Politics of Culture* (2013), regarding the defining impetus of literary and cultural production in the African context. According to Tsaaior literary "production in and about Africa [is shaped by artefacts from within and] outside the cultural orbit of the continent" (iv). Amid that hybridisation, orality, as in Gappah's novel, "engages in a robust and mutually beneficial and catalytic relationship with the written tradition" (Tsaaior xvi). More so, Gappah's insertions of textual elements from Shona and ancient Greek in order to articulate experiences and perceptions of albinism, unfold in the manner that recalls Bakhtin's proposition on how texts engage in dialogic relationships. In one of his popular works, *Speech Genres & Other Late Essays* (1986), Bakhtin contends that (and I personally agree), texts live only by encountering one another and that, "[o]nly at this point of contact between texts does a light flash, illuminating both the posterior and anterior, joining a given text to a dialogue" (162). Here, Bakhtin's grand idea is that when signs of former texts are alluded to in the subsequent text, they open possibilities to transform reality. This observation echoes Kristeva's assertion in which she notes that a text does not just assemble utterances from several texts, but rather that the merging of these texts engages them in some processes, ideological struggles where they can "neutralize one another" (*Desire* 36). Here, Bakhtin's and Kristeva's assertions imply intertextuality as an avenue for earning the performative agency, "a site of permanent openness and resignifiability" of socially pre-established truths (Butler,

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<sup>34</sup> I use the term in relation to how Clotho, one of the Greek's Fates spins death, fate and misfortunes to mortals ([https://www.greekmythology.com/Other\\_Gods/Minor\\_Gods/Clotho/clotho.html](https://www.greekmythology.com/Other_Gods/Minor_Gods/Clotho/clotho.html))

“Contingent” 50). However, in the view of Quayson, as stipulated in *Postcolonialism: Theory, Practice or Process?* (2000), when symbols from one system are referred in a next text, “it is not entirely possible to disengage the new usage completely from their implicatedness in circuit of authority in the indigenous domain, they rather contradictorily reproduce the dominant [meaning in the text they are reused in]” (92). In other words, Quayson implies that the referred symbols from one text may saturate the new text in which they are embedded with their original meanings, that might remain unaltered. As I later demonstrate, Quayson’s insights seem valid regarding how traces of Shona and classical Greek mythological tropes semantically affect the way we interpret Memory as a moral agent and the text’s capacity to resist narratives bringing about social subordination of relegated individuals. The tropes seem to introduce their original connotations in Gappah’s text, which, as I argue, configure the woman (Moira) who gives birth to a child with albinism (Memory) in contradicting terms. Memory is introduced as an agent without freedom to decide the course of her life.

As Memory narrates the story of her family – her blood parents and siblings – we note that naming is Gappah’s essential representational technique employed to illuminate issues related to agency and stereotypes associated to PWA and albinism. Some of these names bear traces of literary and/or mythical figures. Moreover, the names signify the manner through which Gappah’s novel re-utilises Greek and Shona narratives to affirm Bazerman’s eloquent suggestion that authors do “create [their] texts out of the sea of former texts that surround [them]” (83). In Gappah’s novel the name of a character from anterior texts epitomises an earlier text and limns her characters’ experiences. As narrated, Memory’s siblings have adjectival names (Gift, Moreblessings and Joy). These names suggest her parents’ desire for happiness, which they never achieved, given the series of incomprehensible deaths that almost erased the family. However, names such as Memory and Moira, which are names of Greek goddesses, seem thematically to echo their original Greek meaning in Gappah’s novel. They serve as premonitions of respective characters’ agentive roles and behaviour. In the narrative Memory is also referred to as “Mnemosyne” (2). Such a reference recalls the Greek goddess of memory, whose mnemonic power is signified by the protagonist’s ability to memorise and narrate her story and Moira, as said earlier, refers to the three Greek goddess of Fate. Germane to my discussion is how the name of Moira, Memory’s mother, frames her character as though she impersonates the roles and deeds of the three Greek goddesses, the Moira (also Moirae or Moirai) who control mortal’s destiny. For example, Moira, “[by] extension”, means ““The Apportioners,” i.e., the ones who give to each his own [...] portion of life [...]” through

controlling their fate and destiny.<sup>35</sup> Similarly, in my view, Moira in Gappah's narrative symbolises the dispenser of death and misfortune to her children, including Memory, whom the character of Moira frames as lacking agency to alter her destiny. Notably, understanding Moira's character requires an awareness of the significance of her name, Moira, which is also intertwined with or complemented by ideas from the Shona spiritual aspect of *ngozi*. Moira and her child, Memory, experience a sense of being cursed individuals, whose lives and those of their descendants are predestined to suffer unescapable despair. In the novel, Moira believes that she inherited a curse through which she and her family are being haunted by *ngozi*, "an angry spirit" of "a dead man" (249). According to Memory, this is because, "an ancestor of [Moira] had killed an ancestor of her first husband" (249). Consequently, "My father's mother was told that something had to be done, the debt to be paid. A life for a life" (249). Moira thus "[had to] be given over in marriage" to the family of the murdered to appease the *ngozi*, an angry spirit of the dead man, to avenge the "murder committed before [Moira] was even thought of" (249). However, Moira abandoned the covenant and married Benson, illegally. Then, the unappeased *ngozi* must "wreak havoc [on Moira and her generation]" who too are cursed to suffer "every day of [their] life" and to be haunted by "endless death and despair" (249-250). The quotations above clearly allude to Moira's character in terms of the mythical roles of the Greek goddesses of fate. And through *ngozi* she seems preordained to apportion her destiny and misfortunes to her family. It is by considering all these elements that one may look at Moira as though she spins her curse and manipulates fate to entrap those who come into contact with her, analogous to the way the Greek mythological goddesses of fate, the Moirae, spin fate and limit the lives of mortals. All these intertexts from Greek and Shona cosmology imply the notion of fate, that a human being can be controlled by some external or spiritual force. In particular, the reference to the Shona aspect of *ngozi* brings to mind John S. Mbiti's ideas that in African cosmology, ancestral spirits such as *ngozi* control "family affairs, traditions, ethics and activities" (82) for they "warn [...and] rebuke those who have failed to follow their spiritual instructions" (88). It seems then, even though we may interpret *ngozi* as a technique through which Gappah invokes the injustices women endure, such as arranged marriages, one also notes that the novel's recourse to *ngozi* and the Greek mythical figures, "Moira", unfolds in a manner which seems to afford the narrative agency that is performatively ambiguous for it also seems to affirm Moira, Gappah's character, as definitely the culprit of divine retribution. Additionally, a close observation of such intertextual insertion implies that Moira and her child, Memory, are incapable of altering their preordained despairing lives.

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<sup>35</sup> [https://www.greekmythology.com/Other\\_Gods/The\\_Fates/the\\_fates.html](https://www.greekmythology.com/Other_Gods/The_Fates/the_fates.html)

As Memory reminds her listeners/readers, *ngozi* deals out retribution by destroying fields, animals, family progress, making “children [to rot] in their mothers’ wombs” and leads to a “cycle of endless death and despair” (249-250). These presumed misfortunes are accentuated in the life and experiences of Gappah’s characters, thereby entrenching rather than destroying the perception that a woman who gives birth to a child with albinism is cursed, and that Moira’s curse is perhaps also infecting her family and her child with albinism. For example, whoever comes into contact with Moira must encounter misfortune or death, relegating Moira to the unfortunate role of an impersonator of the Greek goddess of Fate — determining the future and lives of other characters. According to *The Book of Memory*, Benson, Memory’s father, lost his job as a carpenter, and his family’s cow dies mysteriously through drowning. Furthermore, his family emphasises that Moira will bring nothing to their son but tears (250). As though supporting this claim, the misery in Memory’s family follows through an endless cycle of violent deaths in the form of various drownings.<sup>36</sup> Initially, Moira’s first born, whom Memory “will now never remember”, drowned (250). Later, Gift, the youngest son, dies, and Moira confesses that the *ngozi* of her first-born dead child “had appeared before her and commanded” her to kill Gift (251-252). She then drowns Moreblessings (251) and attempts to drown “[Memory] in a zinc bucket” (253). Later, Moira and Benson “both drown [...] in the Mukuvisi River” and Memory thinks: “Perhaps it was a murder-suicide or mutual suicide pact, who knows” (248). The fact that Moira features centrally in most of these deaths renders the narrative ambiguous and presupposes that the novel and especially the aspect of *ngozi* is open to multiple interpretations: firstly, one sees that she is designated to behave like the goddesses of fate (the Moirae). Moirae, the literary critic Kim Falconer says in “Fate and the Ancient World”, “wove, measured and cut the thread of mortal life in accordance with natural law” (1). Secondly, it is suggested that Moira infects whoever is connected to her. Therefore, she is herself an instrument of *ngozi*, but how is *ngozi* linked to, or delinked from, albinism?

More importantly, the belief in the *ngozi* as being responsible for misfortune is emphasised in Memory’s narrative, regarding her own birth. She narrates: “And then I was born with no darkness in my skin, with no pigment, an albino, *murungudunhu*, with my ghastly whiteness. My mother believed that I had been cursed inside her womb” (251). This telling reflects the presumed *ngozi*’s ability to curse women’s wombs and it offers insight on how albinism is perceived among the Shona people. Thus, through the recourse to Shona and Greek textual elements one sees how Gappah’s use of pre-existent texts unfolds in a manner that affords the

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<sup>36</sup> Deaths through “drowning” is among “strange ways” through which *ngozi* registers its presence. [https://www.thepatriot.co.zw/old\\_posts/reclaiming-our-spiritual-independence-2/](https://www.thepatriot.co.zw/old_posts/reclaiming-our-spiritual-independence-2/).

narrator ambiguous performative agency. For example, the narrative's allusion to *ngozi* not only states the socio-cultural pre-established prejudice against PWA and mothers of children with albinism, but also in a way, seems to affirm the belief that PWA are born of cursed mothers. The indicated texts fail to afford the narrator with the metaphor that would allow her the kind of agency that Kathy Dow Magnus, in "The Unaccountable Subject: Judith Butler and the Social Conditions of Intersubjective Agency" (2006), would regard as capable of bringing about "acts of performative resistance such that the subject can do nothing but resist" (83) — the very things through which Memory's story would have symbolised an utterance determined to dismantle or disabuse the stereotype of PWA being born of a cursed family or that the mother of children with albinism are cursed.

In arguing for the power of intertextual insertions, Charles Bodunde in "Studies in Comparative Literature", states that "each literature or text has the capacity to influence and extend the meaning of the other" (72). This is similar to the case evident in Gappah's *The Book of Memory*, since as we have seen that the original meanings of the Greek and Shona texts she referred to in her novel seem to "extend and influence the meaning" of Memory's tale and her identity ambiguously. Such effect of intertextuality, in Ode Ogede words, signals the author's failure to clearly "repackage existing stocks by infusing them with new life as a new vision reacts to the old at the strategic point of creative contact" (202). Thus, in terms of the performative agency, Gappah's reworking on the aspect of *ngozi* and the goddesses of fate, Moira, in her novel, symbolises an utterance that, among others, is capable of affirming "the bias and distortion of earlier narrations" regarding PWA and women (Lara 171). For the upliftment of albinism and PWA, the alluded narratives would have afforded the narrator with the illocutionary agency to reinvent the woman bearing children with albinism and those born with albinism from being perceived in terms which hinder social and public agency, terms which deny them a positive social acceptance.

However, as Quayson demands, in appreciating literature, critics must establish the fact that literature does more than reflecting reality because, "[i]n reading the social across the literary [...] the crucial index for evaluating any particular configuration of ideas is whether it provides ways of getting out of confusing habits of thought and whether it illuminates new ways of experiencing existence [...] (*Calibration* xiv). Here, Quayson advocates for the performative agency of a text, the capacity to set right what is misperceived — the narrative's potential to reconstruct repressed truth. This assertion forces me to think of any other intertextual insertion that signal "[utterances] of performative resignification" which could have afforded Memory, with the performative agency as the narrator, to "[construct] new discursive realities" (Magnus

88) while at the same time framing her as the narrative agent who resists social subordination of women with albinism and those who bear children with albinism.

Possibly, Gappah's attempts to demystify the idea that Moira as the mother and Memory as her child with albinism are manifestations of the *ngozi's* retribution can be implied in the role played by Lloyd, the man who adopts Memory and whose demise results in her death penalty. When Lloyd, for the first time, fortuitously met Benson in the cemetery bemoaning the death of Moreblessings, Benson tells Lloyd about the curse that plagues his wife who kills her children. In response, Memory explains, Lloyd "said to him that [Moira] was not cursed, that she was ill, dangerously ill and that their children were in great danger. Could he not send [them] all to school? Lloyd asked. Then he could help [Moira] to get treatment" (258). Here, Gappah uses the character of Lloyd, an educated man, to signal her appeal to scientific texts to reinterpret negative "representation of marginalised, excluded and oppressed groups" in cultural narrative (Lara 171). For Memory, Lloyd's explanation signals an utterance resisting or intending to dismantle the perceptions of the reasons for the endless deaths in Memory's family, and the *ngozi's* curse narrative. According to Lloyd, fatalities in Benson's family may be the consequence of Moira's psychological illness, not the *ngozi's* retribution. Lloyd's arguments, which recall scientific reasoning regarding albinism, suggest that the birth of Memory, with albinism, is just a coincidence and not a spiritually predetermined event or Moira's punishment. One could read Lloyd's intervention as affording Memory's narration agency that, in Butlerian terms, resists superstitions and beliefs culturally assigned to the marginalised. Via Lloyd, Memory's albinism is reinterpreted as a dermatological or medical condition. This is when she is subjected to "expert medical care" and her "skin bloomed until [people] could say [she] was beautiful" (144). With this rhetoric, Memory's tale "defamiliarize[s] existing [prejudices or] categories" assigned to albinism and PWA (Quayson, *Postcolonialism* 95). As Ogede postulates, an insertion of intertext into "a new text" can usually influence the later text in a "crucial way" [...]" (203). This assertion implies the semantic power achieved by an embedded intertext. For example, Lloyd's medical discussion of albinism affords Memory the narrative capacity to rectify the description of albinism as a curse. Such discourse therefore humanises mothers of children with albinism and their respective children and serves as the illocutionary act seeking to widen social agency and acceptance of people born with albinism. Performatively, it names albinism as just a medical condition and not a signifier of divine punishment.

However, I wish to further consider Lloyd's promise to send Moira to his friend, a psychiatrist, for treatment (258). Such a promise I suppose is problematic for it can imply that Moira's

mental condition, described as “madness”, to be the manifestation of *ngozi*’s retribution. This implication calls us to consider the view of Terrence Musanga, a literary critic who has explored the character of *ngozi* in his study titled: “‘Ngozi’ (Avenging Spirit), Zimbabwean Transnational Migration, and Restorative Justice in Brian Chikwava’s *Harare North*” (2009). According to Musanga, “[m]adness is one of the ways that ‘ngozi’ uses to register its presence” (783). If this is the case, we thus can interpret Lloyd’s scientific rhetoric as assigning Gappa’s novel “an open-ended problem of interpretation” (Quayson, *Aesthetic Nervousness* 217), for Moira as a woman who has given birth to a child with albinism and her involvement in her children’s deaths, marks her as a facilitator of *ngozi*. Thus, explanations of *ngozi* and Lloyd’s scientific rhetoric above seem to point towards a merging of cultural and medical understanding of the condition of albinism. Whereas the two might initially seem exclusive or different, they thematically reinforce each other and ambiguously (de)humanise women giving birth to children with albinism and by implication PWA. The explanations seem to advance the myth that children with albinism are born of cursed women or parents. This point brings us to the enigma of interpretation and whether we can confidently affirm the performative agency in Gappa’s novel as being fruitful. The representation, where a character without albinism, Lloyd, fails to speak in terms that would empower the one with albinism, Memory, resonates with my discussion in the second chapter. Mutani represents Joan, a figure without albinism as interceding for a child with albinism, but nevertheless is incapable of affording Jasiri agentive images that proves a PWA as a figure with full personhood.

The last aspect I would like to touch on, regarding Gappa’s intertextual insertions, is Lloyd’s views regarding fate, as well as the incidence of his death which I argue performatively signify Memory and Moira as figures with little or no agency to alter their predetermined cursed life. Lloyd’s understanding of fate is captured in a lecture in which he attempts to explain the ancient Greek tragedy of Oedipus, by Sophocles,<sup>37</sup> in reference to the concept of *ngozi* in the Shona’s world view. He delivers this lecture barely hours before Memory finds him dead: a situation which implicates her as the murderer. In the lecture, Lloyd described fate as “forces that shape human lives [...out] of human control” or “something [...] that determines [...] our good and bad fortune, our happiness and sorrow, and, above all, our death” (220). This rhetoric seems to resonate with the ideas proposed by Mbiti who, as cited earlier, notes that there can be superior or divine wills that control lives.

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<sup>37</sup> Sophocles’ *Oedipus the King* relates the story of Oedipus the man whose free will seems compromised by some external forces. The play’s plot unfolds in the manner that realises the preordainment that Jocasta and Laius will bear a son, Oedipus who would grow up to kill his father and marry his mother.

Interestingly, Lloyd indeed acknowledges the presence of *ngozi* when he equates Oedipus' fate with the Shona concept of *ngozi*, whose retributions, as I demonstrated earlier, seem to be replicated in the misfortunes occurring in Memory's family. Lloyd argues:

“Oedipus was pursued by *ngozi*. And it was Antigone's desire to avoid the *ngozi* that drove her to defy Creon and bury the corpse of Polynices. When we talk of fate, we talk of fatalistic visions of human experience, what we mean is that the most important forces that shape human lives are out of human control.

“It's to say that there is something, an external force that controls the rules of our lives, that determine the things of particular importance to us, our bad and good fortunes, our happiness and sorrow, and above all our death. To have fatalistic sense of life is to hold that our destiny is out of the control of any human being and that non-human actors will always determine the outcomes.

“This is both comforting and terrifying. On one hand, we have no control and can give ourselves over to forces that control us. On the other, we have no control, and are carried along on a tide we cannot control. (220)”

In these quotes, Gappah presents a Western concept of fate and its African equivalent. By merging these aspects from Greek mythology and Shona cosmology, the narrative reminds us of Meeta Chatterjee-Padmanabhan's assertion as captured in the study “Bakhtin's theory of heteroglossia/intertextuality in teaching academic writing in higher education” (2014). According to Chatterjee-Padmanabhan, “traces of prior texts” will always enable posterior texts with “plurality and the articulation of multiple perspectives” (101). In other words, Chatterjee-Padmanabhan's assertion entails that intertextuality populates a text with multiple meanings. In the light of Gappah's intertextual insertions, it is plausible to assume that Lloyd's lecture is serving as an intratextual moment<sup>38</sup> which limns that Moira might have been fated to kill her children and therefore is a culprit serving *ngozi* and that, like in the case of Oedipus, *ngozi* limited Moira's will and capacity to act as a moral agent.

Furthermore, Lloyd's elaborations on *ngozi* in relation to Oedipus's fate can metaphorically be appreciated as foreshadowing the fateful ending of Memory and Lloyd's relationship. Lloyd's problematic death leads to Memory's receiving a death penalty and assigns her the role of carrier of her mother's destined doom, and as one who lacks the agency to escape her presumed inherited destruction. This happens because soon after Lloyd's lecture, Memory finds his dead

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<sup>38</sup> The term refers to internal relations between parts of a single text (see Edmunds, Lowell. “Intratextuality: The Parts, the Wholes, and the Holes.” *Vergilius* (1959-), vol. 50, 2004, pp. 158–169).

body in his room (225). Here the reader sees how Memory's action and choice defy logic as she remarks, "I would transform this accident [of Lloyd's dying while masturbating] into another type, make it seem he had died [...] during a robbery" (229). She reinvents the crime scene to make it seem as if Lloyd had been shot; she "sho[o]t[s] him in the back" (227), pulls the body to the swimming pool and drops him into the water (228). This is an action that results in the court finding Memory guilty of the murder and sentencing her to death. However, as Memory later imagines her incomprehensible acts, it is a thought she testifies how her agency was compromised by an incident which implies that she had been compelled by fate. Her claim: "It is hard for me to explain [...] what I thought I would achieve [...] It is this governing thought that led me to my wild plan. I would make it look as though he had died accidentally [...]" (227), forces us to rethink the nature of the force that controls Memory's actions against her personal agency and will. The incomprehensibility of Memory's decision to violate Lloyd's dead body, which consequently causes her incarceration, signifies that Lloyd's death was an inevitable event in creating her presumed despairing life or imprisonment, regardless of whether she murdered Lloyd or not. Therefore, what Memory terms as "governing thought" becomes a descriptive synonym of a controlling force, (pre)determinism, beyond her personal control. It works as a metaphor of fate which compels her to enter the family *ngozi*'s presumed state of despair, which she lacks the agency to alter. Her incarceration cements her desolation, following Alexandra's testimony that she saw Memory throwing Lloyd's body into the pool — an act which gets Memory convicted of murder. Such a narrative moment constructs Memory as lacking "sovereign wills", one who succumbs "to inexorable fate or irresistible forces" (Garland-Thomson *Extraordinary* 92). Seen against Lloyd's outlook on fate, Memory's incomprehensible acts propel her towards an unavoidable destiny, which she had limited capacity to alter, as in the case of Oedipus. Therefore, Memory's imprisonment portrays her as a figure submitting to a predetermined life of despair. The imprisonment also signifies Memory as though she "propitiates" the *ngozi* curse. This is so because, "In Shona mythology", as Lloyd lectures, "you can propitiate *ngozi* spirit" through feelings of regret or remorse (219-220). As noted, towards the end of her narrative, Memory regards her imprisonment as something she was meant to undergo in order to be cleansed when she says: "I feel as though I have walked through the fields of fire to emerge into a shining coolness" (262). This comment suggests that that even if the court overturns her conviction, she would have already suffered enough to appease *ngozi*.

Generally, as discussed above, it is difficult to establish whether all intertexts in Gappah's novel afford Memory with agency to subvert myths and demeaning perceptions that deny PWA and

mothers of children with albinism public acceptance. In some cases, the narrator's retelling of these intertextual elements seems to imply that they devalue mothers of children with albinism and profile the character with albinism as one succumbing to superstitious beliefs. They thus affirm myths about marginalised identities and legitimise discrimination against them. This is contrary to the discussion in the prior section on Gappah's insertion of intertexts from religious sources, which allowed the narrator with the agency to resignify or resist pre-established demeaning perspectives regarding PWA.

### **3.3. Oral Intertextuality and Performative Agency of the Narrator with Albinism in Unathi Magubeni's *Nwelezelanga: The Star Child***

In the previous parts of this chapter, I demonstrated that Gappah's *The Book of Memory* deploys traces of anterior texts (mainly, Ethiopian Orthodox, classical Greeks and Shona mythologies) to signify historical and contemporary perspectives of albinism in a narrative set in Zimbabwe. In this section I maintain the same inquiry and focus on Unathi Magubeni's use of intertextual elements from African oral narratives, mainly motifs, names, and characters from Xhosa folklore in *Nwelezelanga: The Star Child*. Magubeni, who is also a traditional healer (*sangoma*), is known for two published creative works: his poetry collection called *Food for Thought* (2003) and *Nwelezelanga: The Star Child*, a novel set in the Xhosa cultural and spiritual context, which is the concern of this study. The novel revolves around the challenges encountered by its protagonist with albinism, Nwelezelanga, as she attends a spiritual calling in a plane of existence where her physical difference (albinism) is regarded as a bad omen and a lesser form of humanity. In his representation of matters related to the protagonist (with albinism), Magubeni alludes to Xhosa cultural elements, including the so-called *ubizo*, the unnegotiable calling from the ancestral spirits to serve as a *sangoma*. Nwelezelanga, as the novel's sub-title, *The Star Child* indicates, is one of the children born different, a trope that resurfaces throughout all the texts studied in this thesis. She is not only talented as a healer, but due to her skin colour, she is "relegated to be an outcast in [the land of the walking dead]" (39). Born of Nokwakha, her biological mother, she grows up with Mama, a *sangoma*, and must die to live another reality. Her story thus recounts her journeys between spiritual and physical realms — ranging from her life in the spiritual land of the all-knowing Qamata<sup>39</sup> to the physical world where she serves Qamata's spiritual calling. This is a mission which Bubi, the Lord of darkness and her spirits Mpundulu, and Mthakathi, oppose and therefore they aim to destroy her. She also narrates her unsuitable relationship with Nokwakha and the midwife. In addition,

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<sup>39</sup> In Xhosa mythical tales, Qamanta (also referred to variously, Tixo, uThixo by other ethnic groups) is a higher being, the supreme god and creator of humankind and "all existent life" (Soga 150).

she recounts her life with Mama, a *sangoma* who shows her warmth in bringing her up along with her spiritual mentor and companion, Nomkhobulwana.

Unlike Gappah's novel that realises as a hybrid of written and oral intertexts from both African and Western contexts to articulate the agency of PWA, Magubeni's novel mainly refers to oral texts from within Africa, especially Xhosa folklore. However, both novelists reuse oral texts that seem to afford their respective novels with textual agency to revisit terms subordinating PWA. Their use of intertexts thus proves the way African authors trust and appeal to the repository of continental folkloric materials, the very things through which, as the African literary critic, Njogu Kimani, says, "pass through values, attitudes" and "knowledge" from one generation to the next (125). As in Gappah's narrative, Magubeni's deployment of oral intertexts might regenerate or echo knowledge of albinism from the remote past. In doing so their novels rewrite issues related to people with albinism and rearticulate their experiences and the way they are perceived. Indeed, both authors adopt and integrate elements of oral narratives into their written ones with varied intensity to echo the view of the Nigerian literary critic, Emmanuel Obiechina, as expressed in "Amos Tutuola and the Oral Tradition". In this particular work Obiechina establishes the way intertextuality operates in African texts. According to Obiechina, African literary writers transform or refurbish "well-known motifs and narrative techniques" from old oral tales for current perusal (87). In my view, this textual regeneration provides these authors' respective narrators (with albinism) with capacity to not only contest, but knowingly or unknowingly, to affirm existing stereotypes about albinism. The point here is that since these novelists transform and refurbish posterior texts to suit their immediate creative purposes, in the process, they also afford their protagonists with the agency, and illocutionary force to shift or restate issues limiting the life and public appreciation of PWA. Such intertextual reuse echoes Bakhtin's idea regarding creative reuse of a posterior text in an anterior one as he argues:

The role of the other's word was enormous at that time: there were quotations that were openly and reverently emphasized as such, or that were half-hidden, completely hidden, half-conscious, unconscious, correct, intentionally distorted, unintentionally distorted, deliberately reinterpreted and so forth. The boundary lines between someone else's speech and one's own speech were flexible, ambiguous, often deliberately distorted and confused. (Bakhtin, *The Dialogic* 69)

In *Revolution in Poetic Language*, Kristeva seems to reinterpret Bakhtin's words above when she describes intertextuality as a transformation "of one (or several) sign system(s) into another" (60). These scholars' respective observations on intertextuality resonate with

Obiechina's claim that the African writers' reuse of orality involves adopting, moulding and/or transforming them in accordance with the authors' needs. Thus, written texts, such as the African novel, become "[permutations of texts or], scraps of texts that have existed or exist around [...because] other texts are present in it, at varying levels, in more or less recognisable forms: the texts of the previous and surrounding culture" (Barthes, "Theory" 39). Such an observation is made manifest in Gappah's book and in the case of Magubeni's *Nwelezelanga: The Star Child* as well, which is at the heart of this discussion and which, as I have said, features elements of Xhosa folklore prominently.

In the following sections I examine whether and how Magubeni's deployment of elements of orality, including traditional beliefs regarding reincarnation and the Xhosa myth of creation, performatively contests or affirms perspectives regarding albinism. I then examine whether Magubeni's allusion to mythical characters (birds) works to reformulate the reader's thoughts and perception regarding albinism as they pertain to traditional healing. Here, I consider how intertextual insertions afford the narrator with illocutionary force to humanise PWA in opposition to stereotypes which construe the life and public acceptance of those with albinism while voicing a multiplicity of beliefs on albinism in relation to traditional healing versus sorcery.

### **3.3.1 Reincarnation, Historical Origin and Perceptions of Albinism in *Nwelezelanga: The Star Child***

In a nutshell, Magubeni's novel can be appreciated as the author's record of his own spiritual context to recall challenges faced by PWA, such as being cast out from human genealogy based on the belief that they "would bring confusion that would lead to the demise of our tribe" (6). This perception, which echoes factors inhibiting the social agency and public acceptance of PWA, seems to be the central concern in Magubeni's novel as he draws from Xhosa folklore to represent the character with albinism, while also offering dialogic and diversified views regarding albinism. This representation, I would say, reflects how "African [oral cultures] can be productively engaged and harnessed in the monumental task of rehumanising [...] humanity [...] of] people who have been [dehumanised] in the course of history" (Tsaaior 9), in this case, PWA.

In *Nwelezelanga: The Star Child*, readers encounter a 13-year-old Nwelezelanga who begins her story by telling us about people's perception of albinism through the names with which she is labelled: "I have many names; my mother calls me 'Nwelezelanga' because of my golden hair. Some call me 'Mhlophe' because of fair almost ginger skin". Others tauntingly refer to

her as “that albino girl” (3). These names tags, “Mhlophe” and “albino”, prefigure social assumptions, views and attitudes which demean and dehumanise PWA. They signal how the protagonist’s personality or intrinsic worth is overlooked and communicate the tendency of society to classify people born different as a distinct social category who is denied their full human identity. In *Aesthetic Nervousness*, Quayson writes about “a discourse of stereotypes and expectations that serve to efface a person’s identity” (2). His words refer to how fictional representations can jeopardise and injure the personhood of people born different, including those with albinism. In Magubeni’s *Nwelezelanga: The Star Child*, such a discourse reflects how characters deemed ‘normal’, as I have shown, label Nwelezelanga, the character with albinism. In Butler’s terms, I particularise these demeaning names or labels as an “address [... appearing] to fix or paralyze the one it hails” (*Excitable Speech* 1). To Nwelezelanga, such names are “terms given to her” but the novel’s intertextual referencing affords her the agency to make “changes or resignifications, which necessarily” reposition PWA “against the status quo” (Magnus 83), when albinism obliterates their personhood.

Interestingly, Magubeni’s representation invests richly in this social subordination of PWA and albinism as he seeks to deconstruct their manifestation by engaging orality. As I demonstrate, he deploys elements from orality to signal metaphorically that PWA (represented by Nwelezelanga) have intrinsic worth and that thus their personality is both spiritual and corporeal. This deconstruction is indicated when Nwelezelanga narrates her birth into the physical world. She says she was born after Nokwakha, her earthly mother, prayed to the all-knowing Qamata saying: “Bless me with a child, my lord, and I will be forever grateful. What is the use of a wife if she can’t bear children?” (5). In this narration Magubeni creates a link between the (yet unborn) protagonist and Qamata, indicating that even in the womb, she is imbued with heavenly qualities. Yet, soon after her birth, the midwife, an “old, wrinkled woman” declares that by being an “albino”, Nwelezelanga is “a bad omen”, a “devil incarnate” and a “ghost of a child” who should be drowned for she will “bring confusion that would lead to the demise of our tribe” (6). Eventually Nokwakha is convinced and tosses Nwelezelanga into the mighty Umfolozi River. This event symbolises the gross misunderstanding of albinism as condition and signifies how the physical, social visibility, and humanity of PWA are effaced. It presents the real hate crimes that are committed as if they represent normal behaviour — a failure to see beyond the physical differences of their condition and to accept them fully (Quayson, *Aesthetic Nervousness* 2), which results in abject misery, resisting the acquisition of meaningful identity and the recognition of their humanity.

As if to resist people's demeaning of albinism as uttered by the midwife, Magubeni borrows from Xhosa spirituality, especially the idea of reincarnation, and alludes to further details regarding the legend of Qamata. Such allusions depict Nwelezelanga as a body that houses a human spirit and a body (with albinism) that is one among many valid bodies created by the all-knowing Qamata who, as footnoted earlier, is regarded as the creator of humankind. In her narration, Nwelezelanga says her spirit had "a [...] residence in the world of spirits" (5), in the kingdom of the all-knowing Qamata, a place where many spirits (formless bodies) await "the call to duty [...] at any moment" (4) to attend divine responsibilities (5). Here, the rhetoric of Qamata opposes the midwife's framing of albinism as a curse, ghost, or devil incarnate. This echoes the point where Kristeva restates the Bakhtinian concept of "the literary word" as "a dialogue among several writings" and that such dialogue alters preconceived meanings (65). Nwelezelanga's recourse to the myth of Qamata enables the resignification of the perception of albinism as non-devilish, it confirms the perspective that a spirit is an essence of a human body and that there is always a spirit inside any physical body, providing Nwelezelanga with the agency to insist on this as she says, "There was always a 'me' more pronounced outside the corporeal image" (9). This is contrary to the notion that people born different are empty entities, as suggested by referring to them as phantoms and ghosts. Thus, to the narrator the rhetoric of Qamata "[produces in her an] enabling response" (Butler, *Excitable Speech* 1), a performative utterance that resists oppressive terms and rehumanises what was rendered less human.

Furthermore, Nwelezelanga narrates that her spirit had already acquired several physical bodies to attend other spiritual callings before her current plane of existence. This telling signifies an utterance that reminds us of Butler's view regarding the question of agency that "focuses on whether norms are consolidated or resignified through their citation" (Stephanie 52). The novel reads: "I'm thirteen years. That is a distortion on its own. I am young yet old; I've experienced the cycle of birth and death more times than I care to count" and "I've donned and shredded many skin colours in my lifetime" (3). This narrative moment in Magubeni's tale signifies his reworking of the belief in the regeneration of spirits, a recurring theme in African spirituality. The motif prefigures the logical acceptance that a spirit registers its presence through living in a physical form; rather, it reinforces the previously mentioned idea where the body of PWA is represented as both spirit and body.

Magubeni's endorsement of the phenomenon of reincarnation merits further discussion. As Lipenga and Ngwira assert, it echoes the motif of the *abiku/ogbanje*<sup>40</sup> regenerative spirits — a

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<sup>40</sup>*Abiku/ogbanje* is "a spirit child that – in a cycle of births and deaths – is said to be born to aggravate its parents in some way" (Rooney 114).

spiritual phenomenon featured in many West African oral and written texts. My aim is to examine whether the conviction is a metaphor for an utterance that performatively affirms oppressive terms regarding albinism. As Lipenga and Ngwira observe, the motif of regenerative spirits frames Nwelezelanga (and by association, other PWA) as being the devil incarnate. Yet, I contend that this very element of reincarnation in Magubeni's novel has the illocutionary force to rehumanise PWA. While I admit that Magubeni's idea of reincarnation is closely related to the recurrent motif of regenerative spirits, chances are Magubeni might have adopted it from other African beliefs, especially Xhosa spirituality, or twisted it to depict his diverse but positive view of albinism. As Tsaaior puts it, by drawing from the "inexhaustible pool of African social/cultural history and body of knowledge", some African writers accomplish literary advocacy for the development of humanity (4). Tsaaior plainly states:

In the African situation, however, the argumentations about the origination of African aesthetics in traditional sources should not be merely self-serving, self-inflicting but should gravitate to an elaboration of how indigenous cultural knowledge production can privilege and galvanise Black peoples on the path of lasting decolonisation, freedom and sustainable development. (8)

Tsaaior's words reinforce the empowering manner in which Magubeni's text resignifies the nature of those described in the novel as the children of the star<sup>41</sup> and by implication the rest of characters in Magubeni's narrative world — the walking dead. Nwelezelanga's and Nomkhubulwana's reincarnations serve as the "performative narratives [...which create] and reconfigure the symbolic order", given their centrality in the narrative as spiritual messengers of Qamata (Lara 23). As messengers of Qamata, the two have been reincarnated in numerous ways, "travelled together to different worlds" (3) and "served the divine purpose in countless ways" (93). They "help those who are ready to go beyond just looking; those who actually see the hidden wisdom" and communicate to the living dead how to heal people as well as interpreting dreams and clarifying other issues (42-43). Such roles, to recall Butler's earlier cited assertion, are agentic and resist metaphysical presuppositions about socially made categories disempowering PWA. Being portrayed as the messenger of Qamata, Nwelezelanga, the character with albinism and by implication PWA are reconceptualised as neither being devils incarnate, nor bringing any trouble, as presumed by the midwife. We thus can appreciate Nwelezelanga as a figure fulfilling a spiritual mission to serve the creator. In the light of this view, we see Magubeni's intertextuality serving as enabling agentic utterance which reverses the "system of signs" which subordinate PWA and bring about "a new articulation of the

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<sup>41</sup> Spiritual messengers.

enunciative and denotative position” (Roudiez, *Desire*, “Introduction” 15). Therefore, although Magubeni’s reincarnation mirrors the motif of the regenerative spirit prevalent in African spirituality, it has been altered to meet a new more appealing demand — to reinvent albinism as a positive identifier. The depiction then frames Nwelezelanga as the incarnation of the Bantu healer; she is someone who came to heal and make people think of humanity beyond looking at physical bodies. Thus, as in Gappah’s novel, Magubeni’s reuse of prior texts, as I demonstrate, permeates his novel with what Lara terms “illocutionary force”, a series of self-effacing powerful speech-acts and engaging discourses consisting of a “disclosive capacity” (Lara 2). Such capacity renders the narrative potentially able to alter readers’ perception regarding albinism. Through reincarnation, Nwelezelanga and by implication Nomkhubulwana are perceived as incarnations of gifted figures. Such rebirths conform to something closer to the Igbo notion of *ebibi uwa* as elaborated by the African philosopher Mesembe Ita Edet. In his article, “Innocent Onyewuenyi’s ‘Philosophical Re-Appraisal of the African Belief in Reincarnation’: Conversational”, Edet elaborates that “*ebibi uwa*” is a term that captures an African belief about the reincarnation of a child prodigy, and this notion, he says, is prominent amongst West Africans. Edet adds that, in “explaining child prodigies”, the Igbo people believe that “the [prodigy] child is a reincarnation of a deceased individual, an intelligent, crafty and successful person from his lineage” (82-83), as opposed to a devil incarnate (*abiku* or *ogbanje*). These are the implications of Magubeni’s tale as it narrates the personhood of Nwelezelanga via the legend of Qamata. In *Nwelezelanga: The Star Child*, the rhetoric of Qamata becomes a speech act through which Nwelezelanga resists oppressive terms denying PWA public appreciation.

We can also read reincarnation as Magubeni’s technique through which Nwelezelanga and Nomkhubulwana are narrated as equal personalities, irrespective of their physical difference. As Nwelezelanga puts it, they are half-sisters who “have many things in common”, ranging from being “[...children of] the great spirit of Qamata to [...]" (4), “act[ing] as vessels in communicating the absolute truth of all eternity” (42) to the fact that they “die in order to grow in another reality” and physical forms (126). Therefore, the endless rebirth of their spirits in various physical bodies suggests that a person’s physical form is a mere temporary dwelling of the core of humanity. Notably, this teaming-up of bodies deemed to have incompatible physical appearances, but intrinsically spiritually equally gifted, metaphorically recalls Tobin Siebers’s assertion that a body is just the “means by which we convey who we are from place to place” (7) but which I suggest has less capacity to speak of one’s full personality. Hence, what unites us as human beings is not our physical bodies but the spiritual attachment. Nwelezelanga

articulates this claim thus: “inside us lies a radiance, a most magnificent presence and it is this inner essence that we all justly desire and seek union with” (127). Indeed, Nwelezelanga and Nomkhubulwana value each other equally as intermediaries between the all-knowing Qamata and the world of the walking dead.

Therefore, by alluding to Qamata’s legend and the motif of regenerative spirit, Magubeni not only “situates the text within history and society, which are seen as texts read by the writer, and into which he inserts himself by rewriting them” (Kristeva, *Desire* 65), but also equips his novel with speech acts similar to those Lara describes as signifying the “struggle for recognition” (129) by the marginalised. Their recognition is realised when the reader perceives that “one’s identity is acquired only by means of [...] acceptance of who we are through others” (129). Likewise, Magubeni’s use of intertextuality, up to this juncture, seems to suggest that Nwelezelanga and other characters as bodies who trace their origin from the same creator, the all-knowing Qamata, are spiritually related in their humanity. Such a speech act affirms people born different as being definitely human beings, contrary to derogatory terms that injure their personhood.

### **3.3.2 Albinism in the Hands of Sorcerers and *Sangomas*: “Refracted Reality” in *Nwelezelanga: The Star Child***

In the previous section, I demonstrated how Magubeni’s intertextual reuse of orality reinvents his protagonists with albinism as positive stereotypes. However, the novel too seems to have lapses in interpretation that suggest complexities in the representation of bodies deemed different, because bodies thought to be different “in the real world already [incite] interpretation” (Quayson, *Aesthetic Nervousness* 36). In addition, the complexity entails the fact that, as elaborated earlier, “literary representations [do reflect and/or refract realities] with varying emphasis of both an aesthetic and ethical kind” (Quayson, *Aesthetic Nervousness* 36). More so, the refraction can be positive or negative — positive because defaming stereotypes relating to human differences can be challenged and negative due to, as we shall see, representations that appear to typify human differences, thereby distorting reality. Such negativity may imply that ethical emphasis may overshadow the aesthetic demands of a work. As my discussion reveals, intertextuality has the agency to refract reality since the social and historical meanings of the texts alluded to may populate the subsequent text with distorted or inconsistent meanings. This performative view of texts is supported by Barthes’s statement in his often-cited essay “Death of the Author”, that “a text is not a line of words releasing a single ‘theological’ meaning [...] [because its meaning is influenced by] a variety of writings, [...] that blend and clash” (146). The blending and clashing thus increase multiple implicatures of the

text. This phenomenon seems evident in Magubeni's novel, especially in his (de)construction of albinism as a ritual signifier, a modus through which Magubeni's novel performs contradicting speech acts or illocutions.

Such contradicting speech acts, or illocutions are made manifest as I presently examine how Magubeni, who is himself a *sangoma* (traditional healer), alludes to Xhosa healing practices and dark magic to (de)construct the belief that body parts of (and) PWA have efficacy in superstitious rituals and traditional healing. I consider how such intertextual insertions afford the novel the agency or voice to exonerate traditional healers accused of motivating the mystification of albinism, thereby influencing the "demand for the body parts of PWA used in rituals by traditional healers, known as *muti killing* or black magic, juju".<sup>42</sup> My analysis focuses on how Magubeni patterns folkloric characters such as the midwife, Mpundulu and Mthakathi<sup>43</sup> (agents of evil spirits, Bubi<sup>44</sup> the lord of darkness) versus the *sangoma* (representing African traditional healers) to denote opposing spiritual forces through which the novel (re)signifies different but converging perceptions about the humanity of PWA. I argue that Magubeni uses names of characters to allude to only dark, evil spirituality and to magicians who prefer to use body parts of PWA in their evil rituals. This representation is established to vindicate *sangomas'* and midwives' services and practices, which are allegedly claimed to cause ambivalence about the nature of PWA. However, the vindication is marred by the fact that Xhosa folkloric material seems to work as speech acts with injurious illocutions. As I show, there are moments in the narrative through which Magubeni's intertextual insertions of folkloric materials imply that the novel declares and affirms albinism and other bodily differences as markers of ritual perceptions. This ambivalence echoes Barthes' ideas, as cited above, regarding the ambivalent function of intertextuality whilst being an enabling device of dialogic articulation.

In the previous section we noted that traditional healing as symbolised by the midwife is depicted as condemning PWA, as deserving to be destroyed because they might bring disasters. We are thus tempted to perceive African traditional healing, (especially midwifery<sup>45</sup> and

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<sup>42</sup>News report featured in the *Mail Guardian* <https://mg.co.za/article/2017-09-20-the-killing-of-people-with-albinism-is-driven-by-myth-and-international-inaction/>

<sup>43</sup> According to Robert Godfrey's *Bird-Lore of the Eastern Cape Province* (1941), *Mpundulu* and *Mthakathi* (also *Impundulu* and *Umthakathi* respectively) are creatures associated with dark magic, witchcrafts and deaths among bantus of the *Eastern Cape* (2, 59). In Xhosa folklore Mpundulu "is a vampiric creature associated with witchcraft, often the servant or familiar of a witch or witch doctor, which attacks the witch's enemies". <https://educalingo.com/en/dic-en/impundulu> while Mthakathi is a "witch or wizard; a practitioner of evil magic; an evil-doer" <https://dsae.co.za/entry/tagati/e07053#mthakathi>

<sup>44</sup> Bubi (also *ububi*) means evil in Xhosa.

<sup>45</sup> In some African societies children with albinism are condemned to death or maltreatment resulting from midwifery advice (Thomas and Makama 87).

divination), as exacerbating the hostility towards people born different as it signifies them as a form of plague (Quayson, *Aesthetic Nervousness* 7) and echoes myths and beliefs which codify PWA as objects of superstition. However, later in the narrative, Magubeni seems to draw a line between traditional healing which honours PWA, and dark magic, which he frames as practicing human sacrifice, which values the use of body parts of those deemed different. Meanwhile, Magubeni alludes to names and roles of foul spirits featured in Xhosa folklore (Lord Bubi, Mpundulu and Mthakathi) to articulate conflicting realities on the efficacy of human sacrifice, in particular including bodies of PWA. The author's introduction of these characters' names presents yet another instance of intertextuality. This assertion echoes Kevin Paul Smith's statement in *The Postmodern Fairy tale: Folkloric Intertexts in Contemporary Fiction* (2007) that,

[a]n allusory character name is an example of an intertextual reference that can be located on the surface of the text. The signifier used to refer to a character in one text is recognisably the same as the signifier used to refer to a character in another text. As allusions go, this type of allusion is [...] explicit, [if] the reader recognises the name is also used in another text". (26)

In Magubeni's novel, the belief that body parts of people with albinism have efficacy in spiritual rituals is narrated along with the mention of "Mthakathi" and "Mpundulu". These names refer to evil characters as narrated in Xhosa's oral traditions where they are associated with dark magic and evil roles. Magubeni deploys these evil characters to signal the view that only sorcerers and not true *sangomas* would use body parts of people with albinism as objects in their rituals. In the novel, Mpundulu and Mthakathi are spirits of dark magic and servants of Bubi, "the lord of darkness" who "had created himself" (47) and "appointed the high priest Mpundulu, and high priestess Mthakathi as commanding superiors of the wicked empire" (48). This band of foul spirits seduces lost and gullible souls of servants of the almighty Qamata and have succeeded "to corrupt the midwife" from being a faithful servant of Qamata to serving the lord of darkness through killing the children born differently abled (67). She had, as we have seen, ordered Nokwakha to kill Nwelezelanga, a child with albinism. This telling presents the midwife as a traditional healer whose connection with Mthakathi and Mpundulu frames her as a sorcerer and whose order to kill, associates her and other sorcerers as practitioners of

[h]uman sacrifices [...] done deep in the forest and up in the mountain caves, all in the name of Lord Bubi. Children are preferred in these blood sacrifices by the witches of dark magic and children with albinism are the most prized as there is a belief that

immortality will be gained in the everlasting life through drinking their blood and cutting certain body parts to make foul medicine. (49).

With these nuances we see the narrative agency created by intertextuality working to undermine the single view that traditional healers are engaged in sacrificing people with albinism and enabling plurality of perceptions of truth and reality. Such plurality echoes the Bakhtinian view that intertextuality is “serious truth-seeking by means of a plurality of voices [...] celebrated in the dialogic novel” (Alfaro 269). The author’s allusion to Mthakathi and Mpundulu thus enables the illocution that *sangomas* are different from sorcerers who practice human sacrifice, objectify, and undermine people with albinism. The allusion functions as a speech act declaring people with albinism as human first and not as objects of traditional healing. This is further highlighted when we read beliefs and practices championed by the lord of darkness in juxtaposition with the beliefs and rituals of healing held by Magubeni’s *sangoma* as servants of Qamata.

In the novel, the role of a *sangoma* as servant of Qamata serves as a speech act to humanise people with albinism. It is portrayed by Mama, a *sangoma*, whose healing services are “a call to honour the commands of the high one” (18). Mama’s service honours and humanises people with albinism, in direct opposition to their objectification at the hands of the sorceress. For example, when the midwife, the representative of Bubi, threw Nwelezelanga “down the flowing river to” die (7), it was Mama who rescued Nwelezelanga from drowning. She resuscitated and “fed [her] different concoctions to bring [her] back to life” (8). Again, it is Mama who reunites Nwelezelanga with her biological mother, Nokwakha, after killing the midwife. The legitimacy of Mama, as a more humane *sangoma*, is beautifully painted when Nwelezelanga recounts Mama’s personality as she dances to radiate “highness and lightness of spirit” where she “changes like waves of light showing off supreme charisma, grace, humility, love and lightness of being” (37). This depiction signifies a healing and kindly environment. It indicates the role of the *sangoma* in helping those with albinism. To recall Bakhtin’s ideas cited earlier, Magubeni’s novel serves as a text with multiple voices, some of which can alter socially acknowledged truths regarding albinism. One of those voices is the one contesting the view that it is *sangomas* who use body parts of people with albinism, while the services of *sangomas* are actually rearticulated as beneficial to people with the condition and society at large.

However, as Quayson notes in *Calibration*, the portrayal of human difference always seems to disorder “the smooth flow of the aesthetic domain’s ethical negotiation. [Because] the [difference] always enjoin a response, one that in an unreconstructed social domain is dominated by affective dissonance rather than awareness” (121). Likewise, Magubeni’s

representation of two opposing spiritual powers (the human magicians and the dark forces) and their respective relationship with albinism manifests as a performative act that might affirm albinism as an encryption of extra<sup>46</sup> divine significance. That depiction seems to distort the reality regarding albinism. As for example, Mama's healing rituals use non-human sacrifice. She prescribes her customer by saying:

‘In order for me to start the healing process, you will have to appease the ancestors with a goat and that will be a symbol of the working relationship and connection between our ancestors. You will need to bring three cocks for [the initiation ceremony]; one should be red-feathered, one white and one grey. We will also need candles for the evening ceremony and maize to make fermented sorghum beer.’ (90)

This kind of healing metaphorically suggests that more divine powers have been bestowed on individuals with physical difference than others. More so, in a flashback, which depicts the midwife as a servant of Qamata, before she becomes a sorcerer, she is depicted as claiming:

Over a period of time, the midwife noticed that there were special souls being born across the land; babies that have old souls and an incredible awareness of what is. These children were in some way handicapped for the reasons she could not comprehend. Some couldn't speak properly and had difficulty in communicating verbally. Others were deaf and some were blind; they were born as outcasts but had an uncanny ability to see things that others couldn't see. She noticed that these divine powers were more endowed in children with albinism (65).

This narration recalls Quayson's observations, cited earlier, that African societies mostly configure human physical difference as a signifier of ritual insight and that there are cases where representations of reality concerning bodily differences are refracted to match socially constructed 'truths.' This supports my view that Lipenga and Ngwira's claim that some incidents of narration in Magubeni novel unfold in a way that reappropriates albinism with otherworldly characteristics that propel the incomprehension of people with albinism. However, I insist that these otherworldly characteristics can also be embraced as endowing the novel with a multiplicity of implications, which as demonstrated earlier, are indeed the means through which Nwelezelanga is recognised in a positive way and appreciated. Thus, in terms of the narrative agency, the conflicting representation of albinism in relation to traditional healing and dark magic signifies the manner in which Magubeni's novel, like Gappah's, endorses

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<sup>46</sup> Here "extra" conveys that while all children of the star, Mama, Nwelezelanga and Nomkhublwana have divine significance in Magubeni's fantastic world, Nwelezelanga, the character with albinism is uniquely elevated as such.

contradicting performative agency. Such conflicting agency seems on the one hand to affirm and on the other to contest stereotypes regarding albinism and people with albinism. We can thus read Magubeni's intertextuality with reference to the Bakhtinian dialogic view of life, which is founded "on a vision in which language embodies an ongoing clash of ideologies, worldviews, opinions and interpretations" (Allen 28). This view considers a novel that simultaneously presents contradictory speech acts, views, and meanings. Similarly, in Magubeni's text the rewriting of his spiritual world is smeared with ambivalence that suggests conflict in his (de)construction of strongly held views in his society of human difference seen as divine favour.

### **3.4 Conclusion**

In this chapter, I explored the way intertextuality as a literary tool affords the authors of the novels the means to (re)signify and voice multiple perspectives of albinism and the perceptions and experiences of PWA. I considered whether those perspectives and experiences, as manifested through intertextual insertions, have performative agency or illocutionary forces to resist, challenge, state, or affirm social ideas and stereotypes bringing about social subordination of people with albinism. As the discussion reveals, intertextuality is an essential tool through which Gappah's and Magubeni's protagonists signal various perspectives and experiences related to people with albinism. Furthermore, intertextual insertions in these novels work as powerful speech acts to limn experiences and perspectives related to albinism and people with albinism — speech acts that serve to be agentive in an enabling way, or in a disabling one. They provide the narratives with the capacity to resist, revise and challenge various stereotypes subordinating people with albinism. Regarding this role, intertexts provide spaces of narration through which the narrators of the two novels assert themselves and other people with albinism as normal human beings, and not as cursed individuals and/or signifiers of disasters. Additionally, some of the intertexts, I argued, have performative agency that presents negative stereotypes of people with albinism, while some of the positive affirmations echo the narratives that reject the humanity of people with albinism.

## CHAPTER FOUR

### SOCIALITY<sup>47</sup> AND AGENCY: NARRATING LIVED EXPERIENCES WITH ALBINISM IN AUTO/BIOGRAPHICAL NARRATIVES.

#### 4.0 Introduction

In *African Philosophy and the Otherness of Albinism: White Skin, Black Race* (2019) Elvis Imafidon notes that “ideas about albinism in African traditions”, have often negated the humanity of PWA and interfered with their socialisation (*African Philosophy and the Otherness* 2). These ideas, fuelled by, for example, myths, rumours, superstition, and related discourses, configure PWA as “beings produced from the anger and punitive measures of supernatural entities” (Imafidon, *African Philosophy and the Otherness* 104). Imafidon adds, people might avoid “associating with [PWA]” because they believe PWA may “suffer[...] from the same vengeful anger that brought them into being” (*African Philosophy and the Otherness* 104). Consequently, many PWA are lonely and isolated, a state which may affect their lives from birth, as illustrated in the fiction discussed in the previous chapters.

Proceeding with my research’s concern, this chapter interrogates how agency of PWA is configured and reconfigured in a selection of life narratives. The chapter analyses four auto/biographical accounts, two in written and two in short documentary filmic form, by or of subjects with albinism and their “related others” (Smith and Watson, *Reading* 86) to explicate how sociality, or lack thereof, impacts on their agency and personhood. I examine how the narratives disclose and/or denounce socio-cultural factors delegitimising the social inclusion of PWA in the African ontology. The two written autobiographical accounts by South African subjects are “Dare to Dream” by Vuyiswa Kama and “I am a Human Being-Flesh and Spirit” by Mandisi Bongelo, and both are included in the collection *Looking Inside: Five South African Stories of People Living with Albinism*,<sup>48</sup> edited by Shirley Gunn and Zukiswa Puwana (2009). The collection “is the result of a collaboration between the Human Rights Media Centre” and the “Western Cape Blind Association” to raise awareness of albinism and visual impairment (Gunn and Puwana 1). The other three personal narratives by Nomande Ngcizela, Lucky Jackson, and Vinkosi Sigwegwe are not discussed here for reasons given below. The five subjects all have albinism and are “partially sighted” (1). These intersecting conditions inform my continued engagement with ideas from Disability Studies (employed in previous chapters). As the title indicates, these personal accounts are not only concerned with disability, visual

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<sup>47</sup> I use ‘sociality’ in accordance with B. Scot Rouse’s definition of the term as advanced in his study, “Heidegger, Sociality, and Human Agency”. According to Rouse, sociality entails “the condition of living and understanding oneself amidst social relations to others” (1).

<sup>48</sup> Henceforth referred to as *Looking Inside*.

impairment, or albinism, but *Looking Inside* suggests that these life narratives are also about self-inquiry, each mapping a journey of development in retrospective first-person mode. Being unable to source a similar collection or another book (autobiography, memoir, biography) by or of a subject with albinism from Southern or East Africa in English, I agree with Charlotte Baker and Patricia Lund's observation that the collection, *Looking Inside* draws attention to a dearth in publication of life narratives by subjects with albinism living in Southern and East Africa ("The Role of Fiction" 283). The two short documentaries studied in this chapter are set in Rwanda, both are titled *I Will Never Give up on My Albino Children/BORN DIFFERENT*,<sup>49</sup> produced by *Afrimax* English,<sup>50</sup> and available on *YouTube*. The first, *IWNGU-1* was uploaded on 8 October 2020 and the second, *IWNGU-2* was shared on 23 October 2020.<sup>51</sup>

In choosing *Looking Inside* I was further encouraged by the editors' comment in the Introduction, which states that the aim of the book is "to expose prejudice and counter [...] negative perceptions" which heighten persecutions of PWA (Gunn and Puwana 1). A similar agenda is upheld by *Afrimax* for their production of *IWNGU-1* and *IWNGU-2* – to introduce vulnerable subjects "to the world so that they can receive support from different volunteers".<sup>52</sup> Vivifying their stated activism, all these texts situate albinism, subjects with albinism and their immediate family at the centre of their narratives. All the accounts included in *Looking Inside* narrate lived experiences with albinism and several short documentaries on *YouTube* represent experiences of African PWA, but I selected Kama's and Bongelo's accounts because their discussion of albinism greatly draws attention to issues of sociality and agency while the two short documentaries<sup>53</sup> exhibit arresting cinematic qualities similarly inclined. Therefore, these texts crucially relate to my thematic concerns with social relations or lack thereof, and each story significantly enlightens of agency.

As I said, in my analysis of the chosen texts, I explore "sociality" as "the condition of living and understanding oneself amidst social relations to others" (Rousse 1), and which "is *constitutive* of the core features of human agency" (Heidegger cited in Rousse 1, original

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<sup>49</sup> I abbreviate the titles and number each documentary separately (according to dates shared) to distinguish between the two texts, cited in this chapter as *IWNGU-1* and *IWNGU-2*.

<sup>50</sup> *Afrimax* is an online platform "owned by *Afrimax* Publishers & General Enterprises Limited, a registered private company dealing with publishing weekly Kinyarwanda newspapers" and *Afrimax* English deals with contents produced in English translation. (<https://www.youtube.com/c/AfrimaxEnglish/about>)

<sup>51</sup> As I was concluding my thesis, another short documentary produced by *Afrimax* TV using the same title was released on *YouTube* (on 19 June 2021) but time constraints restricted an exploration of this video.

<sup>52</sup> <https://web.facebook.com/afrimaxenglish/>

<sup>53</sup> There are longer documentaries from East African but those that are easily obtainable are mostly by western producers/directors e.g., Noaz Deshe's *White Shadow* (2013) and David Darg's *Lazarus* (2019). My focus in this chapter is on life narratives by or of African subjects with albinism and their relational others, produced and published by Africans. To date, my attempts to obtain long documentaries by African directors e.g., Lupita Nyong'o's *In My Genes* (2009), were unsuccessful.

emphasis). Moreover, my understanding of agency, discussed in previous chapters, is further underpinned by Bronwyn Davies' definition. In his study, "The Concept of Agency: A Feminist Poststructuralist Analysis", Davies regards "agency" as "the ability to recognize discursive constitutions of individual self and identity to resist, subvert, and change the discourses through which one is being constituted. It is the freedom to recognize [...] that no discursive practice [...] can capture and control one's identity" (51). The chapter argues that, in the selected texts, practices which impair an individual's sociality may result in loneliness and isolation (terms defined in the theoretical section) experienced by PWA and that such conditions may hamper their agency. I further contend that encouraging, supportive social relations may make PWA feel affirmed, their uniqueness embraced, and their agency activated. Lastly, I demonstrate that filmic representations of subjects with albinism are agential because they describe and condemn practices that might foster the social exclusion of PWA, while viewers' comments on the filmic texts' presentation provide further agency because they give voice and recognition to the respective subjects whose individual experiences are narrated.

#### **4.1. Theoretical Points of Departure**

As I stated in Chapter One, there is a hiatus in scholarship that focuses exclusively on literary-cultural life narratives of and by Southern and East African PWA. I bring written and visual narratives together in this chapter to broaden the scope of criticism that explores representational mediums and engages in a contract that deals with albinism and PWA, focusing on matters of agency. The current chapter is informed by Miya Picket Miller's arguments in her doctorate dissertation, *Un-Othering the Albino: How Popular Communication Constructs Albinism Identity* (2017). Miller studies personal narratives from "TEDx talks presented by albinic, Black fashion models, Diandra Forrest and Shaun Ross" (123) — both American celebrities. Adapted from this dissertation is Miller's article, "'Other' White Storytellers: Emancipating Albinism Identity through Personal Narratives" (2019), which uses G. Thomas Couser's notion of "emancipatory rhetoric" (123) to discuss the performativity of the two American models. As Miller remarks, the two subjects "utilize [their] personal narratives to un-otherize (emancipate) from the stereotypical 'albino' identity and highlight the complexity of race and difference-making in our [American] culture" ("Other' White Story Tellers" 123). Building on Miller's exploration, my current chapter addresses a slightly different concern — not particularly on race but on "difference of body colour" (Imafidon, *African Philosophy and the Otherness* 2) and "difference-making" discourses that undermine PWA's sociality and agency in African contexts.

My discussion of how human interactions impact agency is informed by various theorists. I rely on philosopher and political thinker Hannah Arendt's and the feminist scholar Sarah Drews Lucas's discussions of loneliness, isolation, and agency. Complementing these scholars' respective ideas are Imafidon's postulations on African philosophy – of difference and the marginalising dangers embedded in African ontological thought – which are partly theorised from his own experience as a PWA. I also employ Couser's and Suzannah B Mintz's respective arguments on the representation of disability in life narratives to discuss the discursive power of personal accounts in relation to albinism. Lastly, my interpretation of the short documentaries echoes the assertion that “documentaries provide a space to challenge the myriad of simplistic representations” or then the “misrepresentation of African life and societies” in (western) media (Ayisi and Brylla 125). Consequently, I explore how the video texts, and their respective viewers' commentaries, deconstruct ideologies that foster social exclusion and dehumanisation of PWA within the African world.

Specifically, I draw on Lucas's article “Loneliness and appearance: Toward a concept of ontological agency” to define and discuss notions or conditions such as loneliness, isolation, and agency – how these conditions are narrated in the selected texts. In expounding how Arendt's conception of agency implicates extra-political dimensions of agency, Lucas accepts Arendt's proposition that human subjects are characteristically endowed with “elementary confidence” (Arendt, quoted in Lucas, “Loneliness and Appearance” 710) to “appear in the world in the first place [uniquely]” (“Loneliness and Appearance” 710). However, Lucas advances the notion of the “elementary confidence” (which she renames as) “*ontological agency*” by arguing that agency “is an irreducible and constant capacity of every individual, no matter how deeply silenced or oppressed she may have been” (“Loneliness and Appearance” 709); individuals whose ability to exercise agency depends on sociality or lack thereof. Lucas expounds:

I put forward an approach to this question that neither reduces action to pure politics nor reifies political norms by offering a negative definition of agency—by asking what might it mean to *lack* agency completely? I argue that the absence of agency is the condition of loneliness. I will define loneliness, after Hannah Arendt, as non-appearance before others. If loneliness is the failure to appear as a self in the world, then it follows that we can conceive of appearance in the world as a kind of agency. (“Loneliness and Appearance” 710, original emphasis)

I employ Lucas's notion of *ontological agency* to examine how sociality or lack thereof contributes or interferes with the agency of subjects with albinism and their relational others,

as narrated in the selected texts. Furthermore, Lucas defines “isolation” as a “condition” which arises when the political realm is impoverished; that is, when individuals are no longer invested enough in shared interests and concerns to act in concert” (Lucas, “Loneliness and Appearance” 711). I use these ideas to establish whether the subjects (PWA in the studied texts) experience loneliness, isolation or feel excluded from the social world. Notably, Lucas argues that when a person experiences loneliness and feels excluded, they may “lose the sense that they have something unique to contribute to the world in common” and “they feel *superfluous*” or unneeded (“Loneliness and Appearance” 711, original emphasis). Such feelings, I argue, may affect their agency.

Much as Lucas’s postulations on loneliness and isolation and what these conditions suggest about sociality, compromised sociality and agency, are valuable for the argument being advanced in this chapter, I refer to Arendt’s various works (see in the discussion in the analytical sections) to demonstrate that supportive social relationships may enable some of the subjects studied to affirm their individuality and exercise agency. Arendt, herself a victim of politics of exclusion, has written extensively on subjects who have lost a sense of communal ties or relations with their immediate societies. Her ideas are particularised on political subjects but are equally valuable in understanding how agency of subjects with albinism can be compromised or rather strengthened by human interaction, sociality. Arendt’s fascination notions, such as “isolation”, “uprootedness” and “superfluosness” (Arendt, *The Human Condition* 475), are thus evoked in my study to explore how loneliness and/or social interrelationship impacts agency of subjects with albinism. For Arendt, an isolated subject is less a social agent for there is no one they could act with (*The Human Condition* 474). Such a person also endures “loneliness”, the feeling that she/he is abandoned and “deserted by all human companionship” (Arendt, *The Human Condition* 474). Arendt further clarifies that an isolated and lonely individual plunges into “uprootedness”, the “loss of a place in the world recognized and guaranteed by others” (*The Human Condition* 475). What is even more important regarding the issues of sociality and agency, as far as Arendt’s thoughts are concerned, is her view that that the experience of uprootedness has power to make human agents superfluous, to make them feel as though they do “not belong to the world at all” (Arendt, *The Human Condition* 475) and so their acts, speeches and lives become meaningless. Thus, I recall Arendt’s ideas to demonstrate that sociality or its lack thereof may create the (im)possibility of agency for subjects with albinism.

The chapter brings Lucas’ and Arendt’s thoughts into conversation with Imafidon’s views on how Africans think of PWA and “being” (*African Philosophy and the Otherness* 4). Of interest

is whether such thinking propagates the inclusion or exclusion of PWA as human agents. Imafidon notes that in many African communities PWA are isolated from spheres of social interaction because they are “seen [...] as not fitting within the categories of human beings due to [their] unusual nature” (*African Philosophy and the Otherness* 38); consequently, most of them lead a lonely life (*African Philosophy and the Otherness* 104). My understanding of some African philosophical perspectives is that in some cultures, even non-human subjects are included in conceptualisations of African ontology.<sup>54</sup> However, I reflect on Imafidon’s arguments to analyse how some African ontological perceptions might compromise or maintain the sociality of a subject with albinism and might also interfere with their exercise of agency.

One of the key aspects of the narratives examined is how, as life narratives, they are a way of voicing or writing to dispute prevailing, skewed narratives about albinism. Thus, to examine the discursive formations in the studied life narratives, I evoke Couser’s idea that personal narratives are a form of “counterdiscourse”<sup>55</sup> (*Recovering* 90), i.e., they have the capacity to talk back “to patronizing and marginalizing (mis)representation” of people living with somatic conditions (*Signifying Bodies* 31). The counter discursivity of life narratives is well stated in Couser’s argument as explained in *Signifying Bodies: Disability in Contemporary Life Writing* (2012). In this detailed exploration, Couser informs about the power of life narratives in countering stereotypes associated with bodily conditions as he writes the following:

Disability autobiographers typically begin from a position of marginalization, belatedness, and pre-inscription. Long the objects of others’ classification and examination, disabled people have only recently assumed the initiative in representing themselves; in disability autobiography particularly, disabled people counter their historical objectification (or even abjection) by occupying the subject position. The representation of disability in such narratives is thus a political as well as a mimetic act—a matter of speaking *for* as well as speaking *about*. (Original emphasis 7)

What this comment suggests is the fact that life narratives give subjects the chance to speak and depict themselves in their own terms. However, while it is possible that personal narratives may also lack this potential, I nevertheless explore whether the studied narratives challenge pre-established “stereotypes and misconceptions” (*Signifying Bodies* 31) concerning albinism as one of many somatic conditions. To support Couser’s idea, I also deploy Mintz’s argument advanced in *Unruly Bodies: Life Writing by Women with Disabilities* (2007). She argues that

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<sup>54</sup> In “African ontology”, Chijioke Uzoma AGBO cites Plecide Tempels who writes, “envisages a hierarchal ordering of forces reflecting their primogeniture with God at the apex; then man (living and departed); animals; plants; and minerals” all interacting in harmony (53-54).

<sup>55</sup> Couser’s original spelling

when women recite their stories, or another's story, such recollections are endowed with "revisionary possibilities" or capacities to "critique dominant assumptions about the kinds of social roles" and positions women with somatic conditions should take (Mintz 15). Therefore, narrating or having one's story narrated is an agentic act which reinscribes agency, and marks bodies as sites of resistance.

Lastly, in examining the two short documentaries I consider the assertion made by critics of African documentary films, Florence Ayisi and Catalin Brylla, as advanced in "The Politics of Representation and Audience Reception: Alternative Visions of Africa". Ayisi and Brylla clarify that an "African film" has social political significance for it "emerges from postcolonial struggles to redefine and counter cultural misrepresentations" of Africa and Africans, which "are reductive and even offensive" (125). Furthermore, Ayisi and Brylla see that the major aim of African "documentari[ans is] to demystify and de-exoticize African subjects through narrative structure and themes" (125). These scholars contend that an African documentarian should not only aim to reflect but to set right that which it visualises as opposing narratives that its viewers might have. I echo this view to unfold the way the studied documentaries expose and contest ontological ideas undermining persons with the condition.

In the forthcoming sections, I consider how the respective texts employ various methods and modes of narration to express an understanding of lived experiences of PWA. I first discuss Kama's "Dare to Dream" to interpret the ways in which her recollection of personal and social encounters conveys an understanding of how experiences of loneliness and isolation curbed her personal and social agency, of how agency transforms her as she matures, and how her narrative gives agency to other victims of (violent) oppression, notably women with albinism. The focus is on specific parts of her recollection that convey insights into childhood experiences, her sexual encounters, and her life as wife and mother. Thereafter, Bongelo's story, "I am a Human Being-Flesh and Spirit", is read to ascertain what it reveals of social relations, familial and communal, which allowed him agency from a very young age and granted him the assurance to assert himself as a PWA. Afterwards the chapter interprets *IWNGU-1* and *IWNGU-2*. My discussion of these two texts highlights the following points: it ascertains how ontological perceptions of albinism invalidate and exclude PWA from societies; how each narrative (and viewers' comments on the two films) speak to audiences in modes that may reconfigure those perceptions; and how social and discursive figurations of albinism are narrated (through practices of mothering) to demonstrate aspects of agency.

## 4.2. Sociality and Agency in “Dare to Dream”

All people irrespective of who they are may experience feelings or conditions of loneliness and isolation at some stage of their lives, depending on the particularities of their socio-political and personal contexts (Lucas, “Loneliness and Appearance” 711). However, individuals with albinism suffer loneliness and isolation more often, because they face “peculiar existential challenges” such as “the fear of rape”, physical and verbal attacks, stigmatisation, and forceful segregation, which may worsen their sociality and subject them to “undesired singleness” (Imafidon, *African Philosophy and the Otherness* 6). Moreover, myths such as that women with somatic conditions are “insufficient models for ‘normal’ behaviour or activity” and are “incapable of providing adequate care for their children” (Mintz 20) can further affect the sociality of women with albinism. Additionally, perverse stigmas, and patriarchal discourses about wifhood and motherhood associated with PWA, as my discussion of Vuyiswa Kama’s narrative shows, are among the factors that fueled compromised sociality and created conditions that initially impeded her agency and full social integration. Kama’s lived experiences illustrate how growing up within a family and a community without “[f]riendship, love, support [...], and other intimate<sup>[56]</sup> forms of recognition” fails to “provide the confidence necessary” for subjects to exercise their agency (Lucas, “Loneliness and Appearance” 718). The situation imperils Kama’s sense of self for a protracted period of her life.

As an autobiographical account, Kama’s narrative adopts the first-person mode of narration.<sup>57</sup> In the often-cited work on life narratives, *Reading Autobiography: A Guide for Interpreting Life Narratives* (2010), Sidonie Smith and Julia Watson speak of the importance of the narrative mode “I” often used in auto/biographical texts. Smith and Watson observe that this mode, the “I” perspective of a real, living subject “assures the reader” that the story they read is a “credible disclosure” (28) which conveys an understanding of what it feels like to live with the condition described in the given tale, say a real experience of albinism vis-à-vis an imagined truth. Thus, in reading autobiographical accounts, what the reader encounters are “claims about a referential world” or “*the* world” and not a representation of “*a* world” evident, for example, in novels (Smith and Watson, 10 original emphasis). Such a self-reflective, retrospective autobiographical account compels Kama’s readers to trust and accept the version of her recollected subjective experience that relays conditions of isolation and loneliness. This way,

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<sup>56</sup> A desire for loving, caring, parental, sibling, and social relationships.

<sup>57</sup> As previously mentioned, Kama and the other four subjects whose stories are included in *Looking Inside* told their stories to interviewers, Nzuzo Qaji, Zukiswa Puwana and Shirley Gunn. Their accounts were then transcribed by Qaji, Puwana, Malatisi Jajija and Marjorie Lewis (2).

the reader might credit her tale as a verifiable ‘truth’ of how her social circumstances impacted on Kama’s sense of self and her journey of becoming.

Kama’s narrative unfolds chronologically, mapping her development from childhood to maturity. She begins her narrative with facts and anecdotes of her birth. Born (in 1950 in Cape Town) to Sibonisile Kama (her father) and Morgiana Nosipho Xhoseka (her mother), “who became Mrs Kama” (13), Vuyiswa Kama was the first of eight children — the only one with albinism. Her story mainly recalls her relationship with family members, supposed ‘friends’ of the family, teachers, lovers, husbands and her children. The following discussion dwells on how these different people played a role in shaping Kama’s identity and what her account suggests of the possibility of agency.

From birth, Kama’s life was troubled. Her parents were shocked by “this white child”; “with a strange colour” who brought depression to her mother and evoked suspicion in Sibonisile, the father, saying: “This is not my child; it must be the child of the Greek you work for” (13). Ironically, we learn that Sibonisile’s “great-grandmother” had albinism, but he regards PWA as “animals” (17). His great-grandmother had once kissed him and “he washed his face [...] for a whole week” (17). In “Some Epistemological Issues in the Othering of Persons with Albinism”, Imafidon elaborates on some of the reasons behind social cultural marginalisation of people born different (especially those with albinism) in the African context. One among these reasons, Imafidon contends, is that PWA are marginalised because people without their condition find it “difficult to subject social representations [of albinism] to critical evaluation and rational validation, and hence, the deeply entrenched ignorance [about albinism] goes unchecked and unquestioned” (“Some Epistemological Issues” 375). As implied, this state impacts on the welfare and livelihood of PWA. The relevance of this observation is evident when Sibonisile, with his dominant patriarchal attitude, assigns blame for the form of ‘otherness’ evident in the child to his wife, accusing her of infidelity, yet the condition is inherited from his bloodline. Sibonisile offers a slick explanation of his misconception of what albinism really is — a genetically inherited condition — and eventually is estranged from his daughter with albinism. Following the birth, Sibonisile, who believes that the baby will be the source of misfortune to his family, “wrote a letter to his parents in the Eastern Cape about the predicament of his wife having given birth to this white baby whom he wanted to call Nontsomi” (13), meaning storyteller<sup>58</sup> or explained, in this case, as “quite a story” (13). Kama’s paternal grandparents responded with great understanding, knowing “there is a history of Albinism reaching to their great-great grandparents” (13), and insisted on naming the child

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<sup>58</sup> Nontsomi is of Xhosa origin and means “Poet/ Storyteller” (see <https://www.names.org/n/nontsomi/about>)

“Siyavuyiswa – we are happy” (13), but Kama’s parents and later, her siblings, continued to reject and neglect her (14).

The dispute between parents and grandparents on whether Kama should be accepted into the family circle, and how she should be named, as well as Sibonisile’s reactions reflect Imafidon’s comment that many Africans “instinctive[ly] fear” PWA as “something unconventional” (2) and as “cursed, inferior, not deserving of relations” (*African Philosophy and the Otherness* 104). Imafidon’s observation explains some of the reasons for the exclusion of PWA from supportive human relationships, without which (I will show) Kama became “withdrawn and disinterested in almost everything” (15) from a young age. Her experiences and consequent behaviour are indications of how poor sociality compromised her agency within the family.

It is only when Kama starts school that she receives some “attention and love” from certain teachers who “loved brilliant and genius” learners (21). Kama’s comment suggests that she is proud of her mental capacity — indicating an awareness of her intellectual agency and how others appreciated her as an intelligent person (22). However, circumstances at home remained dire. She remembers, “there [was] no bond, no love, no tolerance, no understanding between me and my siblings” (14). This lack of intimacy at home, she says, ensued because her parents “rejected and neglected [her]” (14), and they never showed her siblings “how to love and protect” her as a unique person (14). She adds: “My mother sometimes called me *inkawu* – an ape – in front of [my siblings]” (14). Agency is exercised when a subject has the “capacity for free, creative interaction” (Lucas, “Loneliness and Appearance” 713), but Kama’s parents have “eradicated” such a possibility. Because of her parents’ obstructive treatment, Kama says, her siblings “grew up believing that if the very person who carried me for nine months could call me by this name and not love me, how could they” (14). Imafidon talks of “ableist linguistic representation of albinism in African societies” (*African Philosophy and the Otherness* 47). Such representation registers in labelling and it “remains one of the worst nightmares of a person with albinism” (Imafidon, *African Philosophy and the Otherness* 47). As the phrase “an ape” infers, like the father, the mother in a single expression animalises the child, and this attitude is extended to her siblings who also (in Imafidon’s expression) “conceive [a PWA as] an ontological other” (*African Philosophy and the Otherness* 6). What happens when a PWA is ontologically othered? Once one is othered, Imafidon says, one is “thrown into [the] world” where he/she faces harmful, discriminatory, and disempowering treatment (*African Philosophy and the Otherness* 97-98), which may undermine his/her agency. Such undermining is revealed when Kama says: “Growing up under these [discriminating] conditions made me broken, sad, empty, without goals or dreams. I cried in bed alone where they could not see me” (14). The

rhetoric of “alone[ness]” used here shows how social discrimination and isolation restricted Kama’s public agency. She was socially invisible because family members never *saw* or acknowledged her as a human child.

Furthermore, Kama recalls, “people prevented me from playing with their children” (15), and throughout her schooling she was slandered, named a “*White Kaffir*”<sup>59</sup> (22). This means that it was impossible for Kama to play with and interact with her peers, while the insult “white kaffir” further excluded her because of her skin colour. Arendt speaks of structural isolation and discrimination — instances where one is excluded from human relations, hence one’s agency is restrained because one has “no place in the world, recognised and guaranteed by others” (*Origins* 477). According to Lucas, it is exactly this place in the world and this recognition that might enable the subject to confidently exhibit her bodily uniqueness in society (“Loneliness and Appearance” 710). Implied here is that by being among others one becomes a social actor — a human among fellow humans. Lack of sociality therefore renders an isolated lonely subject as less of an agent because one is unable to act or voice one’s feelings and desires in the presence of others. Arendt argues that when one is lonely, one is unable to express, for example, “thirst or hunger, affection or hostility or fear” (*The Human* 176). This claim is reflected when Kama narrates how “[social rejection] impacted negatively on [her] life” (15) and is echoed in further recollections.

Undeniably, social rejection had a significant negative impact on Kama’s agency. She elaborates: “I never saw any good in myself or in anybody else” and this state “made me withdraw into a little shell” (15). Lucas explains that isolation usually compromises one’s “basic confidence” — one’s “own capacity to appear to others as [a] unique individual” (“Loneliness and Appearance” 718). Therefore, when such capability is weakened, one fails to confirm one’s uniqueness and consequently life becomes meaningless. Kama’s remark, “withdraw into a little shell”, signifies her self-deprecation and discloses that she lacks confidence in herself. “I never saw any good in myself” (15). This is a typical response of the way a person with low self-esteem responds to their society; consequently, not seeing goodness in “anybody else” (15) produced a double-edged misrecognition. Furthermore, the image of “a little shell” (often used in her narration) and the comment about rejecting others recall Lucas’s ideas that “misrecognition can so easily plunge an individual back into loneliness” (“Loneliness and Appearance” 718). Lucas’s argument is that although “[lonely people ...] seem to be alive”, “they have lost their capacity” to lead a meaningful life (“Loneliness and Appearance” 717),

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<sup>59</sup> “A derogatory and racist term for a person who is perceived as ill-bred” in South Africa (see <https://dsae.co.za/entry/white-kaffir/e07868>)

hence they are limited by their circumstances, and, like Kama, they exist “without goals or dreams” (14). This discourse shows how loneliness subjects one to self-antagonism, “pessimism, social withdrawal, alienation” and “low positive affect” (Ernst and Cacioppo 1). This range of negativities is what undermines Kama’s sense of self-worth, embodied and expressed as: “I asked myself, ‘What is beautiful about me, what is beautiful about an Albino?’ The answer I found — there is nothing beautiful about us” (23-24). With this comment, Kama internalises herself and all PWA as beings without “unique sel[ves]” (“Loneliness and Appearance” 214). The conclusion Kama reaches and the rhetorical question she poses reflect Imafidon’s argument that “families and communities in which we are brought up decide our values, our understanding of the world and things around us, our perception of ourselves and other beings including fellow humans” (*African Philosophy and the Otherness* 96). Kama’s “perception of [herself]” is the consequence of reduced, ruined, or impaired sociality and results in a failure to feel acknowledged and to appreciate her uniqueness. Her personhood and agency were compromised from a very early age. However, we must note that Kama’s narrative is structured in a way that shows that she does not remain in this melancholic state. Instead, the tone of the story shifts towards a more positive note as Kama gradually asserts agency.

Since agency is an innate feature, as Lucas argues, “loneliness cannot be a permanent condition because *it is impossible to eradicate human agency permanently*” (“Loneliness and Appearance” 714; emphasis original). Thus, under certain restrictive conditions (e.g., isolation), one might act agentially if one is striving to live fully. The rest of Kama’s account bears evidence of acts or attempts to be agentic. So, for example, Kama recalls how she played games with herself to give expression to feelings and desires — including her need for a loving environment: “I made myself a cardboard baby, like a cut out picture of a doll, and played with it on my own in a corner; I confided in my baby, I told it that nobody loves or cares about me and that when it grows up I will ensure that it is noticed, loved and cared for” (15). This mother-daughter enactment foregrounds Kama’s own consciousness of how a caring mother should behave (discussed later) and expresses her need to love and to be loved by a caring mother. Smith and Watson remind us that subjects always devise “tactics to manipulate the spaces in which they are constrained” (43). This argument invokes Lucas’s earlier assertion that one is prewired with the capacity to act against constraints. Indeed, through the doll, “the narrated ‘I’” or “subject of history” (Smith and Watson 73) demonstrates Kama’s desire for agency which is expressed in her performance of how ‘a child’ (the doll) should be noticed, handled, and loved. To confide, even in isolation, to an inanimate object is agentic. Even without recourse to psychoanalytic and other trauma therapy, it is clear that Kama’s loving words to the

doll reveals the extent of her trauma of being unloved. Put differently, the enactment questions Kama's negated human capacity where she is deprived of intimately relating to others, and of engaging in a reciprocal relationship in which she could exchange her social needs — the urge to existentially feel others and be felt by others in a deserted world. Playing with the doll captures Kama's desire “to take part in the play of the world” (Arendt, *The Life* 40), and illustrates her attempt to negate loneliness, and to affirm herself as a living person — voicing her feelings to something inanimate perceived as human.

My preceding analysis demonstrates how isolation and loneliness can imperil the agency and personhood of a PWA. These conditions can also impair a subject's ability to display their individuality, their “whoness”, which Arendt defines as “the distinction of each human being from every other human being who is, was, or ever will be” (cited in Lucas, “Loneliness and Appearance” 714, original emphasis). To display such uniqueness, a subject “depends upon [...] fellow creatures to play with, and on spectators to acknowledge and recognize [one's] existence” (Arendt, *The Life* 19). So, when a subject like Kama is socially rejected, cast out of a social world, the act entails that the world has failed to recognise her individuality. Ultimately, her “elementary confidence” (Arendt, *The Human* 57) is imperilled. This lack of confidence is expressed in Kama's self-reference as being “nothing”, “without dreams” and that people of her likeness are not “beautiful” (23-24); she further embodies negative cultural discourses that define PWA as ghosts, animals, the living dead or *zeru-zerus* (discussed and demonstrated in the previous chapters). However, Kama's narrative does not end here. In the next section, I explore how she overcomes social rejection and isolation, vocalises agency and acts with agency.

#### **4.2.1. A Claim for Relationship: The Claim for Agency**

As signposted in the previous discussion, conditions (loneliness and isolation) which restrict one's agency can be inverted. In this section, the focus is on illustrating the truth of this assertion by concentrating on how Kama's agency later self-transforms in her life when she becomes more conscious and informed of the dangers of discriminating social discourses. According to Imafidon, “the estrangement [of PWA] is caused by already existing social structures” which undermine them and “it takes [one's] strong will and determination to live outside such a box of existence” (*African Philosophy and the Otherness* 102). This claim entails that for individuals to oppose the meaning that social norms preassigned them, they should be able to exert their agency. In life writing, this transformation is possible because a subject's identity is rendered provisional and is discursively constructed (Smith and Watson 26) and possibly also influenced by exposure to certain discourses that could impart meaning. Accordingly, as one

matures, one's capacity for understanding social strictures also changes. Eventually, one's choices and the expression of one's desires and needs also change. Relational encounters may further alter one's desires and stimulate or transform perceptions of oneself.

These ideas about transformation and identity development are relevant for my interpretation of Kama's retelling of her subjective experiences later in her life, as an adolescent, woman, wife, and mother. In retelling these experiences (I will show), Kama's narrative echoes the primary title of the collection, *Looking Inside*, which anticipates that in telling her story, she also reflects on her past in order to make better decisions. As we shall see, Kama assesses strictures that circumvent her journeys of becoming. To overcome these, she "Dare[d] to Dream". This ability is foregrounded in the agentic title of her life story, and she frequently uses this phrase in her narrative to suggest that marginalised individuals should challenge undermining discourses.

How does Kama narrate her lived experience as a maturing woman with albinism? She reflects on her sexuality, her desire for romantic love and intimacy, and her experiences as a wife and as a mother. Previously I used intimacy to discuss how Kama, as a younger subject, narrates her desire for loving, parental caring, and a warm social relationship with her siblings. Additionally, I turn to Mark Hunter's definition of intimacy, described as "a broader term that extends analysis into fertility, love, marriage, and [sexual] pleasure" (3). These forms of intimacy are mentioned in Kama's account and convey insight into her personal and public agency. Her sexual encounters, perceptions of marriage and wifehood, motherhood or mothering are narrated to reflect aspects of agentic transformation and indicate how she negotiates the dominant cultural (traditional and religious) and patriarchal expectations of wifehood and motherhood. Wifehood, womanhood, and motherhood are contested notions in African womanist and feminist discourses in literary-cultural representations and critical interpretations (e.g., Nnaemeka; Rich; Haratyan). Kama's views on these topics veer away from the generally accepted. Many African traditions regard marriage or wifehood as something a woman should aspire to; a woman is "encouraged to marry and get children" (Ngcobo cited in Akujobi), to enter a bond which, according to the Nigerian gender scholar and sociologist, Oyèrónké Oyěwùmí, "symbolizes relations of subordination between any two people" ("Family Bonds" 1097). However, Kama, as discussed later, has her own conception of marriage which partly aligns with socio-cultural values assigned to traditional, religious, and legal discourses of marriage, such as those concerned with officiation of the marriage bond, control of procreation and sexuality (28). She envisions marriage as a relational act that might avert loneliness. However, Kama's experiences also remodel conventional patriarchal and traditional

ideas that a wife is subject to the will and power of her husband, that she is relegated to the domestic space, and is reliant on his decisions and under his control, especially once she has borne children.

What particularly interests me in Kama's narration are the ways her account reflects aspects of "empowered mothering" (Haratyan 43), of an individual view of mothering, which diverts from homogenising perceptions of motherhood. The American feminist Adrienne Rich distinguishes between two notions of motherhood, which are interrelated: "*the potential relationship* of any woman to her powers of reproduction and to children" and "*the institution* — which aims at ensuring that that potential — and all women — shall remain under male control" (2 emphasis in original). In her narrative, Kama clearly gravitates towards "the potential relationship" and the way that the implications of this approach relate to homogenising views of women with albinism: she addresses stereotypes, social maltreatment, and myths that are perpetuated in narrations within her socio-cultural context.

In "Violation of Dignity and Life: Challenges and Prospects for Women and Girls with Albinism in Sub-Saharan Africa", the sociologists, Aloy Ojilere and Muhammad Musa Saleh argue that "the mythology of most African societies" consider "women [...] inferior to men" and that "women with albinism in Africa [...] suffer the tragedy of double prejudice and special violations to dignity and life, contrary to standard templates of international human rights" (147). These critics further note about women that those "in Sub-Saharan Africa, those with albinism are particularly vulnerable to rape and sexual violation" (147). These forms of violations and the presupposition that subjects with somatic conditions are incapable of romantic love, sexual relations or parentage (Mintz 150) may affect self-worth and intimate relationships of female PWA. Kama's account (discussed later) demonstrates aspects of these prejudices and violations, but I am interested in the "rhetorical acts" she employs to "disput[e] the accounts of others" to settle "scores" and to "invent[...] desirable futures" for herself and her children (Smith and Watson 10).

Kama recalls a specific violation to her dignity and life by her father's driver, Sakhiwo, who used to drive her home from school in the afternoons. He first befriended her and later abused her sexually. Her recollection reads:

One day [Sakhiwo] opened the door and came into the house wanting a glass of water. I went into the room, and while I was getting dressed, he entered and asked if I needed help with the buttons of my overall. While I was saying "No", he got me into bed and raped me. Everything happened so fast, so quick. He put his hand on my mouth to stop

me crying. I still remember the pain and the bleeding because I was a virgin; I hadn't started my periods yet. (23)

Here, we see patriarchal, hegemonic masculine brutalisation of the female child at its worst — the body of the child, who has not yet menstruated is treated as merely a “vessel” which “carr[ies] and convey[es...reductive] meanings” as inscribed by men (Samuelson 836). Kama tells her cousin, Nonceba Makabeni about the incident. Nonceba tells her parents, but Sibonisilie, who subsequently confronts Sakhiwo, believes the driver's denials and eventually “nobody ever [does] anything” (23). This complaisance demonstrates patriarchal behaviour and collective male-to-male control of the female body — the male perpetrator's denial is accepted as truth while the brutalised female victim's testimony is nullified. One also can also interpret Kama's claim: “nobody ever did anything”, as indicating how her family members hate her—she has albinism. Given such, neither the father, Sibonisilie, nor any other family member could protect Kama or the abuser, Sakhiwo, responsible for rapping her. Eventually, the female *child* (with albinism) is rendered powerless. This bias could also be supported by the father's tendency of looking down upon PWA, and so he trusts the male adult and scorns his own daughter and denies her the agency to address her victimisation. Kama thus is silenced, made out to be a liar. Because of this trauma and ill-treatment, Kama notes: “I went back to school and kept it to myself because I did not want to be stigmatised as a dirty person” (23). This experience brought her “self-hatred” (23), and she “blamed [herself] for the rape” (24). These feelings, all suggesting loneliness, made her “rebellious” (24). During her adolescence she would “sneak[...] out through the window and [...] stayed away the whole night” (24). Rejection by others repeatedly manifests in self-rejection and a rejection of others, as she notes: “I never had a steady relationship when I was young”, “I would use my boyfriends” and “I would hurt them because of those who hurt me before them” (27). Because Kama's life lacks “sentiments of attachment and affiliation”, supposedly the powers “that bind people to one another” (Cole and Thomas 2), she struggles to engage in meaningful intimate (sexual) relationships. Even when Kama becomes involved with her first boyfriend, a relationship which might connote her social acceptability as opposed to when her parents rejected her because of albinism, it is evident how former rejections and abuses she endured continue to haunt her intimate life. Speaking about her first boyfriend, Solomzi Plaatjie, Kama explains:

My very first relationship was just talking, talking. Solomzi Plaatjie, [...] was shy and I still had all the baggage from rape. I was afraid he might find out that I was not a virgin. I acted as if he was not my first love. We broke up because I lied, and I lied because I knew eventually, we would have sex and he would find out I was not a virgin.

He may have been shy to walk in the street with me, because we never did. I took into consideration that I am Kama and that nobody falls in love with Kama, so I always had secret affairs. (30-31)

The socio-cultural values assigned to women's bodies, ideas about virginity, and how these are discursively repeated and enforced from generation to generation among the Xhosa, for whom virginity represents the "purity of a girl before marriage" (Swaartbooi-Xabadiya and Nduna 20) are clearly evident in this narration. Karma movingly expresses the lack of intimacy, the loneliness of her marginalisation as she sadly voices her deeply held belief about herself: "I am Kama and nobody falls in love with Kama"; a self-identification irrevocably linked to her identity, "I am an Albino" — repeatedly voiced in the narrative. The trauma of rejection now finds expression in "secret affairs" (31), another form of self-alienation and silencing. When Kama says: "He [Plaatjie] may have been shy to walk in the street with me, because we never did", the use of "shy" signals a more sympathetic attitude towards the boy's behaviour than might otherwise be implied. Kama does not use, for example, the word "ashamed", but Plaatjie's fear of being seen with her in public signifies shame. What is significant here is Kama's fear of rejection because the comment "he would find out I was not a virgin" seems to be of greater concern than the possibility of shame, of being seen with someone with albinism. Plaatjie's shyness evidently stems from his anxiety of being seen in public, "to walk in the street with me", because albinism is conceived of as "undesired divergence from social expectation" (Shuttleworth and Kasnitz as cited in Brocco, "Albinism" 232).

It seems obvious that albinism, which is visible, and not rape or loss of virginity, which are not always publicly visible, make Plaatjie feel shy. The two incidents, however, deny Kama the public expression of her intimacy and intimate agency, so that the events recalled serve as illustrations of Smith and Watson's assertion that one's "self-presentation in public" is always "governed by cultural strictures" (42), or, as Imafidon puts it, PWA live in accordance with "already established social systems and values" (*African Philosophy and the Otherness* 97). These scholars' view entails situations where one's existence becomes meaningless so that one cannot enjoy life in full; a situation evident in Kama's relationships recalled here. We thus see Kama typifying how people with disabilities are "more vulnerable to 'bad sex'—relationships, which are considered to be [...] disempowering in different ways" (Sonali 2). Kama's reference to "secret affairs" reflects how people with albinism are publicly rejected in her society. The reference further suggests that she struggled, at the time, to express intimacy in public. She is embarrassed and is secretive about her relationships, which suggests she has internalised social systems and values which view the raped and body with albinism as shameful; not worthy of

meaningful, public relationships, and therefore to be deprived of intimate agency. Her experiences of marriage, particularly to her first husband, Fundile Mahlom (discussed later), also testify to such a negative kind of relationship.

Smith and Watson argue that “autobiographical subjects register, consciously and unconsciously, their complicity with and resistance to the terms of cultural self-locating they inherit” (183). This means that by telling their narratives, subjects disclose whether they resist or comply with oppressive discourses. Kama’s narrative discloses her awareness of and resistance to her confining circumstances – narrated in her willingness to choose alternatives – to exert agency. So, for example, she notes: “It was painful accepting I could not change; [to] overcome the ill treatment. *I tried to find ways of coping*” (17, my emphasis). The rhetoric here is reminiscent of Michel Foucault’s maxims of power, advanced in the book, *The Ethics of the Concern of the Self as a Practice of Freedom* (1997), which states that “[w]here there is power, there is resistance” (96) and that “resistance [can make] a revolution possible” (97). These words enable the argument that Kama has sufficient power to contemplate “find[ing] ways of coping” with undermining discourses. Thereby she reminds us of how PWA are motivated by their suffering to go against “socially infused values” (Imafidon, *African Philosophy and the Otherness* 96) which disconcert them. More so, Kama’s resistance to social discrimination is indicative of her subjective recognition that “alienation is [...] a state of inauthenticity because it implies living not by one’s choices and convictions but rather by social structures and values” (Imafidon, *African Philosophy and the Otherness* 102), which are undermining.

To compensate for her lonely and isolated existence, which impairs her right to publicly express affection, Kama makes certain choices that would make her capacity for intimacy and sexual expression public. After a series of secretive, unfulfilling relationships, which did not last because “[w]hen the affairs were getting serious [Kama] pushed them away”, she decides to marry, at the age of “twenty-six” (27-28). Maggie Gallagher avers in her study, “What is Marriage For? The Public Purposes of Marriage Law”, that in many cultures “marriage exists as a public legal act and not merely a private romantic declaration or religious rite” (774). This means that when individuals enter an announced marriage or union, they also publicly proclaim their private commitment and confirm their intimate and sexual relationship. Likewise, for Kama, marriage would bring public recognition, an improvement on the ‘secret affairs’ that she previously had, since marriage would end her ‘aloneness’. She also decided to marry because she was pregnant and marriage would give her status as a wife, legitimise her child, and validate cultural ideas of motherhood.

In her feminist study, “Family Bonds/Conceptual Binds: African Notes on Feminist Epistemologies”, Oyěwùmí writes on the meaning of wifhood in the African context. She elaborates that in many African societies, wifhood is “traditionally [...seen not only] as a transitional phase on the road to motherhood”, but also as a “symbol [...for] relations of subordination between any two people” (Oyěwùmí, “Family Bonds” 1097). Motherhood is however “the preferred and cherished self-identity of many African women” (Oyěwùmí, “Family Bonds” 1097). The latter assertion is valid only if motherhood empowers one, because as Ksenia Robbe contends, in most “African families”, “patriarchal” and other “systems of domination and exploitation have deprived black women of”, what she names after Buchi Emecheta’s terms, ‘the joy of motherhood’” (38). However, regarding how women use “motherhood” in “a variety of ways” to “resist [undermining] signifying practices” (Robbe 38), the forthcoming discussion reveals the extent to which wifhood and mothering undermine or empower Kama’s sense of self.

Kama expresses her marital and social expectations when she first marries Fundile. She says: “I met Fundile Mahlom, a teacher from [...] Eastern Cape.... He fell head over heels in love with me” (28). This idiomatic expression reveals how Fundile presumably felt about her, his acceptance and validation of a woman or a body with albinism, but more significant is what follows: “I can’t really say I was in love with him but *I needed somebody*” (28). My emphasis highlights that Kama’s albinism did not inhibit her human desires for social belonging and so she married for companionship — to counteract her lonesomeness and isolation. In *Love in Africa* (2009), Jennifer Cole and Lynn Thomas assert that “politics of exclusion and inclusion have so often animated affective discourses and practices” (29). For Kama who is firstly socially rejected because of her albinism, Cole and Thomas’s assertion implies people with albinism desire emotional bonding to achieve some social attachment. Thus, the phrase “I needed somebody” displays Kama’s wish to forge social integration and in doing so to earn reciprocal recognition, which defines one as an agent in the world; a world from which Kama was formally excluded because of her albinism, because PWA deserves no social bonds. Kama narrates:

When I fell pregnant with Thando we got married secretly because we did not want him to be an illegitimate child. We went to a pastor, and we signed a marriage agreement. In Xhosa culture, my husband had to pay *lobola* – a bride price formerly paid with cattle now paid with money – but because we did not tell anybody and even though I had waited for him to send his people to pay, he never did. I had my child in April 1978 and we moved to Paarl. (28)

Kama says nothing about whether the payment of “*lobola*” would have impacted her agency. However, in Xhosa tradition the practice can “provide [... women] with a source of status and respect” or “materially bind them to a patriarchal authority” (Shope 69). This contradictory meaning of *lobola* seems to have been replaced by the church marriage, which Kama expected would accord her a respectful union by binding her to a husband, and so as a human agent, to use Arendt’s words, would lead her to be “perceived by somebody” (*The Life* 37). This expectation is revealed further when Kama divorces Fundile because of his sexist, patriarchal attitude, and his infidelity, and then marries Mkaliphi. In this second marriage, Kama still seeks “a sense of belonging and a male figure in the house” (34). As noted, in describing the reasons for getting married, Kama repeatedly says she needed “a sense of belonging”, a “male figure” or “somebody”. The need to find “somebody” remains despite the rejection experienced in her first marriage and is a reminder of the view that an ontological agent needs “human company” (Arendt, *The Life* 74) to authenticate her existence.

I have argued that Kama needs to marry to have “human company” (Arendt, *The Life* 74), to seem human. Would marriage cater for this? Kama describes some of the circumstances of her first marriage and her responses to Fundile’s emotional rejection, verbal abuse, infidelity, alcohol abuse and economic manipulation. Fundile “stopped the [bank] cards and told the shops that” she is “not allowed to buy anything without him” and so Kama “had to lie and steal” (33) to survive and care for her children. Her remark, “I was married but it did not feel so [...], he was never there” (33-34), reveals that in addition to financial imprisonment marriage subjected her to loneliness. Furthermore, Fundile “verbally abused” her (34) and taunted her with his many infidelities. For example, she recalls:

By that time, I was pregnant again. There were ups and downs in our relationship. Fundile was a womaniser. I was devastated when one of his ladies told me that he did not love me, and just wanted my father’s money. The relationship continued after Yandisa, my second baby, was born and then we split up in 1982. He returned the same year apologising to me and saying the world was cruel and that his people were cheats and liars. Our marriage was still on rocky ground when I fell pregnant again with Anele, born in 1983. At that time Fundile was madly in love with *another* girl; they even came to the hospital together to visit and bring me fruits. I considered getting sterilised because I was not going to have anybody’s baby anymore and if my marriage ended, then so be it. Finally, the marriage ended. He just packed his bags and left. (28)

Through phrases like “I was devastated” for “he did not love me”, as well as “Fundile was a womaniser”, Kama’s recollection supports Robbe’s notion that wifhood is “a site of both

control and repression” (36). Kama is publicly humiliated in hospital, and entrapped, but in retrospect she comes to acknowledge Fundile as “womaniser”. At the time, she instinctively understood that the union was not one of reciprocal recognition and that for Fundile albinism did not matter or attract him to marry Kama, rather he only wanted “money”. Therefore, like so many women throughout history, and in diverse contexts, Kama contemplated to use her body to resist patriarchal and reproductive oppression through contemplating “sterilisation” and ending her marriage. As Filomina Steady asserts, the African woman is disadvantaged by a “lack of choice in motherhood and marriage” (cited in Davies and Graves 7), thereby referring to how women endure “obligatory motherhood” (Davies and Graves 9) and to male domination in a marriage. However, Kama overcomes these challenges.

Earlier, the discussion referred to a doll that illustrates Kama’s desire to love and to nurture, and to be loved in return. This is not the only moment in the narrative that illustrates her desire to nurture. She eventually does become a mother and uses that experience to exercise agency. In some African societies the “primacy of marriage and [mother]hood” is “for the attainment of socially recognized personhood” (Smith 160). This assertion presupposes that to marry and to mother a child can be transformative, the point demonstrated as I focus on Kama’s comments about bearing children and mothering, and how these relate to her condition as a woman with albinism and her agentic acts.

Some of the stereotypes that Kama challenges through motherhood include the myths that “disabled women [are ...] unfit for motherhood” (Mintz 5) and so should be “barred from participation in romantic or erotic relationships” (Mintz 10). Kama’s recollection of her labour during the birth of her first child reveals how members of the medical profession, clearly regarding themselves as able-bodied, endorsed aforementioned discourses. She narrates: “When I was pregnant and had to go to the hospital, I heard the nurses making strange comments, like why do I have sex if I am blind. People treat you as if you are not a human being. The nurse mockingly asked what if I had a baby that looks like me” (38).

The nurses’ comments reveal their prejudices against albinism and partial sightedness, reflective of views held by broader society against people with such condition. Ironically, the medical staff are supposed to be well-informed on bodily conditions and disability, but they still discriminate. They perceive the disabled body as undeserving of sexual intimacy and as lacking the ability to bear abled-bodied children. In some African contexts PWA are “murdered to ensure that they do not procreate” (Ojilere and Saleh 147) or are forced to be celibate. Such threatening of sexual and reproductive rights of PWA is reiterated via the nurses’ discriminatory language.

Kama's comment in response to the nurses' ableist and oppressive utterances about her mothering abilities, illustrates her resistance to their prejudice and illustrates her exertion of her maternal agency. She relates her consciousness of care and mothering: "If I had a baby that looks like me, I would show people that he or she *is a human being and bring it up properly with love*" (38; my emphasis). Despite her visual impairment, Kama has more insight into what constitutes a sense of humanity than the ableist nurses and even Mrs Kama's practice of mothering. As Germain Bree insists, women's personal accounts should be read as a distinct genre that enables female subjects to autobiographically "think back through" their mothers' experiences (441). That is, they reflect or challenge their mothers' lived experience through their narratives. Kama's narrative, particularly her response to the nurses' comments, echoes Bree's words especially when it is read against Mrs Kama's practice of mothering. Mrs Kama was complicit in maintaining what Rich would call "an oppressive institution" of motherhood which also was "a compromise of [her] independence" (2). She rejected Kama because her husband "did not like" their baby and because of the way society perceived her child's condition (35). In contrast to this, Kama decides to accept her baby (Thando) before she even saw him, and she promises to treat him with the care all humans deserve. This is a form of "empowering mothering" for it "contain[s] the potential [maternity agency]" to disrupt "oppressive discourses" (Jeremiah 25) which undermine human differences. This mothering practice is evident in how Kama relates with her children — all of them "born fully sighted and perfect", and whom she "raised on [her] own, because Fundile was never around" (31). Crucially aware of how her "children struggled to gain acceptance from other children because of [her condition]" (31), she encourages a sense of righteousness in them. When they "fought with children who laughed" at Kama, she sat "them down and explain[ed] that they needed to accept, without being embarrassed, that they have a mom with albinism, and that if they continued to settle matters with violence they would turn into violent adults" (32). This way, Kama uses "her maternal agency" to challenge "dominant [oppressive] cultures" (Were 63) and extends the primary function of motherhood from bearing children to an authority that can enact social change.

In treating her children with respect and teaching them to respect others, the mother and her children establish a bond, absent from her own youth, in which there is mutual recognition to an extent that she can "share everything" with them (32), including the discussion of menstruation and the trauma of her rape. Such mothering is counter-discursive on many levels. In telling her son and daughters everything, she debunks Xhosa custom, because it is the convention for a Xhosa woman "[n]ot to talk to their sons about periods and rape" (32). Her

account is then agentic— it not only empowers her own subjectivity but also those who are othered by hegemonic discourses, disabled and able-bodied. In empowering mothering, “the child develops within and through interaction with the mother, who must also be a desiring subject. The child seeks recognition, and that recognition must be given by someone who is herself an agent” (Jeremiah 24). It is the reciprocal recognition between individuals that empowers people and gives meaning to their existence. In Kama’s own words, being recognised and appreciated by her own children, “add value to” her “life” (34). The child-mother relationship thus grants Kama the capacity “to express [her] thoughts, feelings, opinions” before others (Lucas, “Loneliness and Appearance” 715). She thus becomes an agent in the social world where she acts with others through talking and thinking, hence her humanity is affirmed.

Although Kama’s narrative comments extensively about how familial encounters shape her sense of agency, her own acceptance as a person is partly influenced by her own choice — “loving oneself” (47), and by other people’s positive influences. Speaking of friends, Kama says: Princess Matambo (a fellow PWA) “taught me not to hate myself and other people” (21) and Vinkosi (also a PWA) “played a significant role in my self-acceptance. *Vinkosi, [...] and my children kept reminding me to believe in myself*” (47, my emphasis). This emphasis underscores how people activate Kama’s agency. In that way, to use Lucas’s words, “the world experiences [her as a unique agent]” (“Loneliness and Appearance” 716). Interestingly her relationship with other people echoes her mothering practices. Kama says: “I found a way of pouring out the love that was within me” through mingling with people at work and “[i]f issues arose, I would be a mediator; I found a way of bringing people together. I turned the negative treatment I received from my parents and my siblings into a positive experience” (26). Despite the fact that her agency was compromised to such an extent that she “shut [her]self off from the world” (39), off from other people, her recollections also show how certain people – her own children, friends, and co-workers – activated her agency and she, in turn, is able to transform them too. They grant her a stage to act *with* them.

In the discussion above, I have explored how unfavourable personal and social conditions, motivated by the fact that she is a born with albinism, instilled feelings of loneliness and isolation in Kama, and how she countered restrictive forces in her life. As demonstrated, the unfavourable social relationships experienced with her family and society members thwarted Kama’s agency from a young age. Sexual experiences and intimate relationships (although were partly destructive to Kama’s selfhood) also afforded her agency for they connote how to some extent her body was socially accepted. But as her narrative unfolds, we encounter a subject who consciously and with resilience decides to agentively rewrite the story of her life, previously

dictated and persistently maintained by suppressive and discriminating socio-cultural forces, value systems and discourses. Kama's narrative thus suggests that "alienation of persons with albinism from self and others", which also imperils their agency, is "caused by the representations of their being in the society in which they are thrown into and the consequent stigmatisation and discrimination" (Imafidon, *African Philosophy and the Otherness* 102). To revise such conditions, one must exert one's agency— "occupy or inhabit a here, a region of being, a sphere of events" (Imafidon, *African Philosophy and the Otherness* 97) because "action through association serves as a bulwark against loneliness" (Lucas, "Loneliness and Appearance" 711) and activates one's agency. Kama's childhood rarely gives her access to this world, nor do her romantic and marital experiences create such an opportunity, but her struggle for the survival and well-being of others, including her children, wins her other people's love and recognition, and this improves her sense of self and agency. Kama's first-person narration speaks of social and familiar rejection and acceptance to show how sociality may influence agency of PWA and shape an understanding of the politics involved in the battle against social marginalisation suffered by PWA and their relational others, such as Kama's children. Non-fiction accounts such as Kama's call for unconditional acceptance of subjects with albinism which will authenticate their ontological agency to the fullest. In the following section, I examine Bongelo's personal account and explore how self-affirmation is strengthened, from a young age, by the narrator's accepting social and familial environment.

#### **4.3. Sociality and Agency in "I am a Human Being - Flesh and Spirit"**

Reading Mandisi Bongelo's story, one quickly gathers how familial relations are central to an individual's self-assertion. In the narrative, entitled "I am a Human Being - Flesh and Spirit", Bongelo recalls how his condition of albinism was readily accepted by his family and by many community members during his youth, an experience that positively affected formation of his subjectivity and agency. I examine aspects of his story that suggest that his social and personal experiences as a youth largely enabled him to escape conditions that might produce loneliness and isolation, and how he therefore could exercise personal and social agency from a very young age.

To establish how social interrelations affect Bongelo's agency, I agree with the assertion that friendship – a cordial relationship "behind every human interaction, whether formal and professional, as in doctor to patient relationship, lawyer to client relationship and the likes, or informal as seen in relationships that are of a familial type" – interlaces people and renders them as capable (Iwuhu 16, 19). I demonstrate that cordial familiarity is an enabling trait that

characterises Bongelo's narrative, although his subjectivity and agency (I will show) were also influenced by prejudice, peer pressure and gender roles.

Born on 22 September 1990 in Cape Town to Nomalinge and Mr Bonisile, Bongelo is the youngest of four sons (Siyabulela, Xolisa and Siyabonga) and brother to two younger sisters (Thembakazi and Xola). Set in rural and urban settings, his narrative describes his childhood experiences as part of a loving family: his relatives, parents, siblings, and a cousin (Thobeka), his childhood friends who swam and herded cattle with him in Zwelendiga and Lady Frere in the Eastern Cape. He recalls his experiences growing up, and his relationships with fellow learners at schools and with community members in Cape Town.

Unlike Kama's hostile relationships with her family and the community, Bongelo's family, schools and community members showed kindness and friendship — “a degree and kind of consideration for others' welfare” (Telfer 238), which accommodated human differences. As the following discussion illustrates, being positively considered accords Bongelo agency to be seen by others and act through and with people in his family, community, and school. Of special interest for my discussion is how Bongelo narrates forms of “friendship”, which, according to Arendt, can make subjects with differences “equal partners in a common world — they together constitute a community” (“Philosophy” 83). How would such a world enable a friendly appreciation of human variation and agency?

Although Bongelo and Kama both have a Xhosa background, Bongelo was born in 1990, 40 years after Kama's birth in 1950. Bongelo was therefore born at a time when society's views of albinism, as the story suggests, had already undergone some change, because Bongelo's family, community, and school environments (in the city) seem accepting of PWA, which suggests some increased level of education and social awareness regarding the condition. Nonetheless, his story also shows that sadly, 40 years later some rumours, myths, superstitions, etc. about albinism persist.

Bongelo's first claim for agency, which also demystifies PWA, is discernible in the story's title: “I am Human Being – Flesh and Spirit”. The title signifies the narrator's agentic entitlement to humanity. Bongelo recounts his story in a first-person narrative, so that the use of the “I” grants the narrative a quality of authenticity and truth, as previously discussed in reference to the work of Smith and Watson. It also confirms his negated subjecthood and ontological status, given the discourses that negate the humanity of persons born different. More so, the rhetoric of the title seems “to offer compelling counter-representation” of albinism by challenging “rhetorics already in circulation that simply reinforce stigma or condescension” (Couser, “Signifying self”

2) such as of PWA as immortal beings. For example, Bongelo voices his awareness of the discursive power of such myths and superstitions by saying: “I have also heard stories that PWA do not die” (118). In using “stories” rather than saying, for instance, ‘I was told’, or ‘I know’ the narrator signals his awareness of, and resistance to, discourses that negate ontological agency of individuals with albinism. Imafidon observes that “[t]he person in African traditions is a composite whole of a number of substances: material, immaterial and even quasi-material substances. He has a body, spirit, mind, and destiny. The physical body is concrete and tangible [...]. The spirit, on the other hand, is the spirit of the individual” (“*African Philosophy and the Otherness*” 37). Thus, when Bongelo claims he is human with “flesh” and a “spirit”, he also asserts his right to living, dying and spirituality. The view is reinforced via this rhetoric: “I believe that I am a human being and have a spirit, I breathe and do everything that others do” and “if *you* die, why won’t *I*?” (118, my emphasis). This claim for humanity, a shared humanity, and spirituality resonates with the African conception of personhood: “I am, because we are; and since we are, therefore I am” (Mbiti, quoted in Imafidon, *African Philosophy and the Otherness* 41). Although every individual is unique, a recognition of each other’s individuality might guarantee everyone the “confidence” (in Arendt and Lucas’s sense) to exist among others.

Unlike Kama’s, Bongelo’s birth and his “difference of body colour” (Imafidon, *African Philosophy and the Otherness* 2) were accepted and celebrated by his family. He explains, Siyabulela, Xolisa and Siyabonga (his siblings) “were amazed when they saw me” and “were happy because every time somebody visited my mother, they would announce that there was a new baby at home. They told *everyone* that there was a new baby at home” (105, original emphasis). The diction: “announce[d]” and “told” “*everyone*” of “a new baby at home” connotes a positive atmosphere indicating the “new baby” was fully and happily appreciated and recognised amongst family members. Bongelo’s family displays “attributes of friendship, such as affection, trust and loyalty”, which are also “part and parcel of kin relationships” (Guichard “Introduction” 6). Bongelo’s kin accepts him with affection and unlike Kama his bodily difference is not singled out for comment. As Ejikemeuwa Ndubisi, an African philosopher writes: “[T]he human person can only authenticate his/her existence as a social being when he/she collaborates with the other in a relationship that is hinged on openness, reciprocity, trust, sincerity, truth, mutuality, respect for the other, justice, among others” (9, original emphasis). That is, these virtues may nurture one’s self-confidence, and because Bongelo’s family practices them, he easily exercises his ontological agency amongst his peers.

Juxtaposing the two narratives – Kama’s and Bongelo’s – affords a clearer indication of the power of social relations in forming a well-anchored self. Kama’s encounters stand in stark contrast to Bongelo’s, considering the emotional and social rejection by her family during her childhood as opposed to the acceptance and affection that enabled Bongelo to confidently claim his agency — personal and social attachment. For example, when Bongelo’s brothers “dropped [him] at the crèche before going to school” (106), where he felt lonely, he expresses his desire to be among other family members. He notes: “The crèche was on a little hill so I could see home and what my mother was doing, and I always cried because I wanted to be with my mother, my brothers and my sister and cousin” (107). It seems then that unlike Kama, whose family members abandoned her, Bongelo’s family warmly accord him times of joy, peacetime, cheerfulness, courage and self-assurance. All these virtues guarantee a positive atmosphere where Bongelo feels valued.

According to Osa Dozie Iwuh, one’s “confidence of being is because others are in being” and being with “[others may assure one] of their solidarity and complementarity without which [they] cannot be” (23). By extension, this maxim means that one’s capacity for living fully is boosted as they act through and with others. Bongelo reveals how friendly relations in Zweledinga added meaning to his life by reminiscing: “I enjoyed those days; they were happy times. We could see the dam in the far distance and when the weather was hot, we would all gather to swim” (107). The dam, with its “dirty water”, is thus a site where the friends transgress and defy their parents who do not want them to swim in this dangerous place. This kind of transgression is common among young children who try to exert their agency. But how is it enabled by friendship? Friendship forges a stronger bond of companionship between Bongelo and his peers, signalled in the use of the plural subjecthood “we”, through which he and his friends earn agency to act collectively and realise their happiness or deliberation.

Smith and Watson suggest that personal accounts are narrators’ agential means to talk “back to the cultural stories that [...script... these narrators] as particular kinds of subjects” (176). Applied to the case of Bongelo’s narrative, this assertion clarifies how swimming with friends enables him to disclose a trait that is part of his true self – boldness. He recalls:

The boys from the village thought I was spoilt because I had stayed in Cape Town. They thought we took things easy in Cape Town. So, I had to go with them and get tough. Women and girls collected the firewood and they had to cook. The boys’ job was to look after the livestock and have fun in the dam. In the morning we had to push the cattle to get water and grass. [...] When our parents told us to look after the livestock that was the time we had freedom to swim. (108)

He further elaborates:

The dam water was filthy; the pigs also used to swim there. The boys did not want me to swim in the dam with them because they were afraid my mother would see, because the mud stuck on my skin and was noticeable. But I did not listen to them; I swam despite their warning. [...] I enjoyed those days; they were happy times. (107)

While the first anecdote supports Bongelo's capacity to prove his ability to his friends, the second one presupposes that Bongelo's skin difference was noticed by other children but viewed not in derogatory terms and situation gave him chance to act together with friends he exerts his agency. Readers sees that despite his condition, albinism, Bongelo too can act equally boldly as his friends, and that just like other children, he can resist or challenge authority. His daring defiance of the group's objections shows how he already, as a child, exercised agency.

Social relationships with friends are key to Bongelo's character formation not just at home, but also in the school space. In primary school, a supportive circle of friends affords him a space to assert himself as a person with abilities and agency. A section of his narrative details how easily Bongelo mingled with other students:

In primary school I participated in a lot of activities, like choir, drama, rugby, cricket, dance, and I played club soccer. When we had events at school like farewell, we did drama on the quad to raise money for them. When they called the drama with the loudhailer to perform, I jumped, and got on stage. When they called the dancers, the *omajayivana* – township dancers – and the traditional dancers, I performed. I was popular at school. (110)

Ontologically, Lucas says that one exercises agency by "being an interlocutor, through thought, speech, or action, with others" ("Loneliness and Appearance" 709). That is, social exchanges give one a space and ability to exert and display one's agency and identity. By participating in singing, drama, and dance, Bongelo becomes an actor who inserts (in Lucas's sense) himself among others, and eventually discloses his uniqueness before others. This way, Bongelo's narrative does what disabled subjects in life narratives do: "to undo and/or overwrite, their prior representation" and beliefs which confound disabled people — when they are framed "as defective, deficient, interpellated as fundamentally alien" (Couser, "Signifying Selves" 2). As the recollection above posits, Bongelo is a figure capable of physical and intellectual endowments like other gifted children without albinism.

As demonstrated in the preceding discussion on Kama, many children with albinism are stigmatised. People think that any interaction with a PWA "can be detrimental" and so they

exclude “persons with albinism from social gathering or activities” (Imafidon, *African Philosophy and the Otherness* 430). Given their immaturity and the inability to distinguish fact from falsehood, children are likely to succumb to these myths. However, Bongelo’s story indicates that the power of friendship afforded him agency to deflate such myths. He states:

As a child, I had lots and lots of friends. Every day when my father came from work, he gave me money to buy a loaf of brown bread. My father buttered some slices with margarine and put it in my big school lunch box [...]. The rest was meant for Siyabulela and I to eat after school. [...] During break time, I collected my friends, we walked to my home, and we ate all that bread that was meant for us after school. When Siyabulela got home, the bread was finished, so he had to cook for himself.  
(109-110)

Here, expressions like “I had [...] lots of friends”, “I collected my friends”, “we walked to my home” and “we ate that bread” reveal the power friendship has—to relocate an allegedly stigmatised identity into one that is embraced and loved. One thus is reminded of Iwuh’s assertions that, “[t]hat which the human person befriends, must be that which he loves”, and that “[f]riendship binds people together in justice, weaving them as one and creating a harmonious existence, which sees every party coordinating itself in sync” (19). As the recollection above indicates, Siyabulela never minds Bongelo sharing the bread that was meant for him with his friend. Bongelo’s contentment thus symbolises an African view of life, where one needs to share his life with others for them to appear human. Among Africans, the African philosopher, Ikechukwu Anthony Kanu says, “life is a life of sharedness. One in which another is part thereof. It is a relationship, though, of separate and separated entities or individuals [...] but with a joining of the same whole” (cited in Ndubisi, “Semiotic” 20). The assertion may imply that these communal relationships accord one reciprocal acknowledgement, recognition and complementing coexistence, hence unique entities appear as humans before one another. The sharing of one loaf of bread by many children is then agentive as it humanises the child with albinism and epitomises how friendship binds Bongelo and friends as one. Additionally, Bongelo’s mischievousness affirms that he behaves and is like other children.

Nevertheless, as I demonstrated earlier, Bongelo is aware of the myths that disrespect PWA in his community. He remembers an occasion where he suffered abuse because of his bodily appearance: “The drunkards in my community sometimes call me names. They say ‘Hey *Inkawu* or *umulungu*’ – an ape or white person. It hurts me [...]” (118). Ape is the same word Kama’s mother used to describe her. However, by using the word “drunkards” and not “people” the narrative implies that people’s inability to think rationally (as symbolised by the assaulters’

drunkenness) is what motivates exclusion of albinism as a valid human difference. That way, myths, superstitions, and hatred that demean albinism subscribe to states similar to drunkenness. This interpretation is suggested as Bongelo recalls the friendly community members' reaction against his rejection, while depicting his understanding of his condition. He states:

My great grandfather had Albinism. It's inherited. Some community members say God created it. They shout at the drunkards who insult me telling them that it is because of God that I am the way I am. They reprimand them and ask, "What would happen if we were all the same? How would you feel if you were insulted?" and the drunken person would apologise to me. (118)

In saying "my great grandfather had albinism", Bongelo signals his understanding of this hereditary, genetic condition, and his position as significant subject in this genealogy. When the community members invoke the spiritual narrative that God created all humans and that therefore they are all "the same" regardless of somatic differences, they question perceptions of 'normalcy'. Couser states that "physical, social, and cultural obstacles" may exclude people born different from the common world (*Signifying Bodies* 33). This view resonates with the way that the drunkards think of albinism, but the spiritual rhetoric (re)articulated in Bongelo's story, signifies that some members (in Bongelo's society) appeal to religious explanation to normalise albinism as a form of humanity. Eventually, their narrative guarantees Bongelo a social inclusion symbolised when the "drunken person would apologise [to Bongelo]". This religious rhetoric is also evident in Gappah's and Magubeni's narratives; in both texts it considers albinism as created by God, contrary to other belittling myths.

The preceding elaboration explains the advantages of friendly companionship in according Bongelo social agency. However, there are pitfalls to the friendships established. Bongelo experiences peer pressure, which he describes as follows:

Grade Ten was very hard, partly because we were doing the new curriculum, and because of the influence of my 'friends'. I would leave home early, meet up with them and we would arrive at school late, when the gates are closed. So we would go back to the township and hangout together. (114)

This transgression is common to youngsters who exert their agency, but Bongelo does it unwillingly. He explains his motivation for doing so:

I did these naughty things with fellow learners so that I could fit in. I did not smoke but hung out with them during school time to prove that I was just like everybody else. You were regarded as a sell-out if you did not do what the other boys did. (104)

The tone, as suggested by the words “naughty things” and “sell-out”, proposes that Bongelo as normal child gives up his power to choose because the desire for social belonging, to “fit in”, overpowers his personal agency. By investing more time in his friendships than in his studies, Bongelo fails “Grade Ten” (114). However, when he repeats the Grade, he resists peer pressure. He declares: “I do not have a lot of friends” because by having many friends “your focus will be on your friendships rather than on your studies. So, I don’t have any friends [...but] I speak to my classmates during lunchtime” (115), and he occasionally asks other learners for academic help and jokes with them (116). This is an example of how Bongelo chooses to be alone without being lonely. It is a choice of “being alone [...to exercise] the sense of absolute independence” (Arendt, *The Origins* 466). Bongelo’s exertion of agency against peer pressure is motivated by his teachers who counsel him, and the family “encouraged [him] to continue with [...] schooling” (114). Utilising his freedom, Bongelo studies hard and performs well. He says: “[m]y father decided to slaughter a sheep and hold a celebratory ceremony because I had passed my exams” (116). Notably, despite financial burdens, his father acknowledges the child with albinism, who might have been abandoned by other male parents like those discussed in reference to the previous texts.

Another shortcoming in Bongelo’s socialisation is revealed as his friends, father, and even the community force him to conform to normative gender roles. He narrates: “I was bullied and teased [by the learners] for befriending girls and was labelled a *moffie*—a derogatory term for homosexual or an effeminate male” (114). Does this bullying, as formulated here, relate to his condition of albinism? Clearly not. Interestingly, it tells us that Bongelo is othered for what is socially regarded as feminine behaviour or sociality, and not his skin condition. In “Disability and masculinity in South African autosomatography”, Ken Lipenga explains that “values of masculinity are imparted onto [...] children by various socialising agents in their societies, including their parents, siblings and peers” (7). It seems then, the same society that accommodated Bongelo’s condition—albinism— “defines which bodies are to be valued” (Lipenga 8). In ableist culture, “the ideal masculine body” is “the able-bodied one” (Lipenga 2). Thus, being “bullied” entails Bongelo should behave ‘manly’ because femininity is denigrated. Bongelo rejects the grounds on which he is bullied, an attitude reflected when he says: “I had to deal with them after school as well” (114). However, it appears that the pressure was too severe and somehow irresistible. He reveals: “My father is not happy with me

befriending girls”, and “I am careful not to be seen comfortably befriending girls” who are “many of my friends” (119). The scenario here is reminiscent of Kama’s fear of being found out for not being a virgin (more than being raped or being a PWA). Then, one sees how heteronormative gender roles impact Kama’s and Bongelo’s agency. However, as Robert Morrell observes, “usually, a particular version of masculinity holds sway, bestowing power and privilege on men who espouse it and claim it as their own” (5). What Sibonile and his friends want is not to exclude Bongelo, but rather that he should display a manly appeal deemed as normal or abled and that will accord him the “patriarchal dividend” (Connell as quoted in Morrell 6), the privilege denied subordinated identities such as homosexuals or effeminate figures.

Even so, Bongelo expresses his agency by embracing some of the perceived virtues of masculinity, such as his desire for initiation. He avers: “Next year, I have to go to initiation school in the Eastern Cape, because I will be turning twenty and will have finished school. Then I will be *ubhuti* —a man” (124). Here “initiation” and being a “man” reflect Bongelo’s desire for the standard of “how men should behave and how putative ‘real men’ do behave, as the cultural ideal” (Morrell 4). This desire also is reflected in his expectation to “get a job”, to get married and have children and live in his “own house” (124). Although naively planned, these expectations speak of his agency, the need to appear like a traditional Xhosa man, the virtues he learns from his “father and mother”— his “role models” (124) — people who had brought him up with love.

Before concluding, I contend that, as in Kama’s practice of mothering, agency in Bongelo’s narrative transcends the focus on only the self. He desires to be a social worker (124), to educate and take care of others — especially those with albinism. Likewise, like Kama’s, Bongelo’s narration – telling his story is an agentic act – is a means of making public the private. The narrative also speaks for others he wants to empower once he becomes a social worker so that they can be transformed like himself.

I conclude this section’s discussion by reflecting on Lucas’s claim that “supportive relationships facilitate [...] agency by providing a world in which the agent can be certain she will appear as herself” (“Loneliness and Appearance” 718). This assertion is implied in how Bongelo’s account depicts socialisation as an aspect of empowerment and reveals how friends (the preceding discussion uncovers) can also impact one negatively. One must give up one’s preferences for the sake of conforming to the identity preferred by peers or traditions. However, for Bongelo, his family and the majority of the community with whom he interacts are friendly, and they authenticate him as human among them. Through a friendly society, Bongelo is not

only recognised by others but becomes an authentic text to undo narratives pre-inscribed to people with disability and albinism. Using the autobiographical mode, he discloses to other subjects, and indeed to his readers, that he is “a Human Being - Flesh and Spirit”. In the next subsections, I examine how two short documentary videos expose and condemn factors that complicate the social inclusion and exclusion of PWA.

#### **4.4. Reading Albinism: “Parent-Child Relationships and Community”<sup>60</sup> in Two *YouTube* Documentaries**

Having examined autobiographical accounts in written form in the previous sub-sections of this chapter, this sub-section continues to explore how sociality can impact on the agency of children with albinism and on their relational others (immediate family) as represented in two short auto/biographical *YouTube* documentaries.<sup>61</sup> Both documentaries are titled, *I Will Never Give Up on My Albino Children | BORN DIFFERENT*. As indicated previously, I use abbreviated titles and number each according to sequence of release date to distinguish between the two. The first, *IWNGU-1*, is a 12-minute film released on *YouTube* on 8 October 2020 and the second, *IWNGU-2*, released on 23 October 2020, is about 10 minutes long. Both documentaries are *Afrimax TV* productions;<sup>62</sup> are set in Rwanda in undisclosed settings; and are themed around parent-child relationships and their experiences with albinism. I define the films<sup>63</sup> as auto/biographical because they are third-person narrations by an off-camera narrator, who occasionally appears on camera as interviewer, and the subjects whose stories are told are afforded opportunities to speak in the first person in Kinyarwanda (subtitled in English). I use the two texts as examples of life narratives in film form that draw attention to discriminating and stereotypical discourses of PWA and matters of agency (Nyamu 1). The PWA in the two films are children and although they are filmed performing different tasks and activities, their respective mothers are the primary interviewees. Irene Nyamu notes: “For children with albinism, the associated stigma is likely to amplify the silencing and constrain their agency to

<sup>60</sup> The quotation in the heading is from Irene K. Nyamu’s article, “Competing intergenerational perspectives of living with albinism in Kenya and their implications for children’s lives”. *Childhood*, May 2020: 1-13.

<sup>61</sup> These two documentaries are primarily narrated in English and when Kinyarwanda is spoken during the interviews it is google auto generated into English subtitles. Translation affords a broader audience. Except for the translating narrator in *IWNGU-2*, who identifies himself as Prince, other members of the production team, the director, or respective interviewees of these films are not named, but *Afrimax TV* claims ownership of the texts (see <https://www.youtube.com/watch?v=TgmRqArPC8w> and <https://www.youtube.com/watch?v=IPak7E3Sv9M>)

<sup>62</sup> According to <https://playboard.co/en/channel/UCIz8TWyIB9MK--tmY18GuQ/about>, *Afrimax TV* Online is “owned by Afrimax Publishers & General Enterprises Limited, a registered [Rwandese based] private company dealing with publishing weekly Kinyarwanda newspapers in Rwanda, namely, *Planet Rwanda*, *Mapigo Vibes*, *The Profile* [...] and [...] *Spoti Xtra*.”

<sup>63</sup> I use films to mean short documentary films as is used by Marcelina Piotrowski in her discussion of *YouTube* documentaries (see “Speaking ‘Out of Place’: YouTube Documentaries and Viewers’ Comment Culture as Political Education”. *Journal of Curriculum and Pedagogy*. 12:1, 2015: 53-72).

navigate their conditions” (3), therefore, I consider how the children’s and their parents’ experiences with stigmatisation are represented and how the respective parents and some community members undermine or cultivate agency for the children with albinism. My critical, thematic comparison of the two films focuses on aspects of voiced narration rather than cinematography; how first and third person narration reduces or asserts agency for the children with albinism or the voicing of the condition of albinism. More importantly, I examine how the films’ thematic concerns “facilitate a space for [socio-]political pedagogy” (Piotrowski 53) and how “audience responses” (Anthony and Thomas 1280) contribute to public education and cultivate agency for PWA. In turning to the pedagogical value of online documentaries such as the two analysed here, I relate the concluding analytical section of the thesis to my discussion of the educational agendas in children fiction, addressed in Chapter Two.<sup>64</sup>

I acknowledge, there are many online short and long documentary films depicting lived experiences of PWA from elsewhere in the regions I study. I selected these two texts, set and produced in Rwanda (a region in East Africa),<sup>65</sup> because, although literary and cultural representations as well as criticism deal with humanitarian and ethical crises such as the Rwanda genocide of 1994 are numerous on the region, albinism in Rwanda has received minimal attention in the media, literary-cultural representations, and albinism-related scholarship. As Christopher J Hohl’s “Albinism in the Social Sciences and Humanities: A Bibliography” (2018) reveals, and at least my own search corroborates, criticism across disciplines often discusses albinism in East and Southern Africa but mostly refers to Kenya (Nyamu 2014; McBride 2014), Tanzania (Brocco 2015; Dave-Odige 2010), Malawi (Paul et al., 2014; Braathen 2006), Uganda (Kelly 2011; Bradbury-Jones et al., 2018 ), Zimbabwe (Lund 2001; Fidelis and Makama 2018; Machoko 2013), and South Africa (Lund and Gaigher 2002; Lipenga and Ngwira 2018), to mention a few. I also selected life narratives in short film form to gesture towards future avenues for research and I chose the two films as examples of documentaries produced in Africa by Africans that advocate for PWA, rather than analysing examples of Western intervention (Niang 213). I read the selected films as illustrations of how African filmmakers intend to “construct a different Africa [...by redefining cultures,] histories, and identities” (Ayisi and Brylla 127). The section considers these films as illustrations of an emerging trend of the “African documentary” practice which “seek[s] to interrogate the African

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<sup>64</sup> In Chapter Two I commented on the educational agendas and pedagogical value of the studied novellas, in this chapter I develop this focus to examine the educational value of audience’s generated comments in the viewer commentary platform of the short documentaries. I consider how the exchanges of comments on albinism may affect agency of PWA, public understanding of the condition, and social acceptance.

<sup>65</sup> “Rwanda joined the East African Community in July 2007” (<https://www.eac.int/eac-partner-states/rwanda>)

experience” through truthful depiction of issues (Ukadike, “African Cinematic Reality” 89) related to albinism. More emphatically, the section inquires whether these films’ viewer generated comments offer discourses which can rewrite socially constructed positions ascribed to PWA’s marginalized identities.

The decision to work with short *YouTube* documentaries and to focus on their pedagogical potential as agentic representational tools – to educate viewers and elicit their commentary – is motivated by Mary Grace Antony and Ryan J. Thomas’ argument that “technological” platforms such as “social networking sites (e.g. Facebook, MySpace) and video-sharing sites (e.g. YouTube) allow[...] for alternative discourses to manifest” because “the viewer is thus simultaneously a user and a producer of media content” (1284). Furthermore, as Marcelina Piotrowski notes, “the pedagogy afforded through documentaries on *YouTube*” in the comment section provides ground for a “mediated context [which] affects how viewers learn and engage with these documentaries and other viewers” through online comments (54). I thus consider *YouTube* documentary viewers’ commentaries as tools or platforms, that according to Grant Andrews “allow[...] for multiple [...] identities to be represented in dynamic ways, complicating the ways in which mainstream mass media often stereotype or distort queer [and in my case albinotic] lives and experiences, and simultaneously challenging the widespread social marginalisation of queer [or albinotic] people” (Andrews 84). These two *YouTube* documentaries are designed and distributed as “online view-on-demand” narratives (Ellerson, “African” 228). Viewers can watch (or download to watch) these videos when convenient and once watched, the two films offer agentic or productive discursive representations which trigger individualised and or collective agency, i.e., speech acts which can destabilise the social marginalisation of PWA in offline spaces. The films are therefore part of “a number of deliberate efforts in recent times — particularly in the last decade or so — to overcome the discrimination against and maltreatment of [PWA]” (Imafidon, *African Philosophy and the Otherness* 111) by providing awareness about albinism to the audience.

My thematic analysis of the representation of parent-child relationships and communal perceptions of albinism or discourses of albinism relates to my analysis of “empowering mothering”, discussed in the previous sub-sections of this chapter. Empowered mothering surfaces as a powerful motif in both films. Mostly because the first-person speakers are the respective mothers, and their accounts highlight their own vulnerability and the vulnerability of their children with albinism. The mothers are significant figures who mitigate agency not only for their children with albinism but for their families, who also suffer discrimination. Their parenting evokes Oyèrónké Oyèwùmí’s contention regarding motherhood, as elaborated in her

work *What Gender is Motherhood? Changing Yorùbá Ideals of Power, Procreation, and Identity in the Age of Modernity* (2016). To this point, Oyěwùmí postulates that “motherhood [has a] unique position in [Africa and] can aid in the struggle to transform the lives of all Africans, but especially the lives of African women and children” (211). Such a claim seems valid, for the accounts voiced by the mothers in these two films explicate socio-cultural systems and related discourses that undermine the agency and personhood of PWA; more importantly, these films also depict mothering practices that counter beliefs and perceptions that seek to undermine agency and personhood of PWA.

As I mentioned, *IWNGU-1* and *IWNGU-2* are respectively set in unidentified urban and rural contexts and each family’ story draws attention to their dire socio-economic conditions and recounts how myths and superstitions about albinism impact their lives. In “Precarity, poverty porn and vernacular cosmopolitanism in NoViolet Bulawayo’s *We Need New Names* and Meg Vandermerwe’s *Zebra Crossing*”, Cheryl Stobie, a literary critic, writes about a kind of representation that draws attention to vulnerable subjects’ economic circumstances, which remind us of the notion of “poverty porn” (Hester’s cited in Stobie 517). Such representations, which deploy “dire conditions” facing vulnerable individuals (including PWA) to “stimulate readers’ [viewers’] impulse for meaningful reflection leading to changed attitudes”, Stobie demonstrates, is characteristic of fictional representations of characters with albinism (Stobie 517), and it surfaces in both films. However, the coming discussion mostly interrogates how these visual texts and the comments exchanged by the two films’ respective viewers voice and or (de)stabilise the marginalising attitudes that confound PWA.

*IWINGU-1* recounts the story of unnamed family, a mother and her nine children, three with albinism. Through on and off camera narration in English, interviewee responses (some subtitled in English translation) and activities filmed, the voiced and filmed footage foregrounds the talents of the three children with albinism and presents the relationship between the mother and her three children with albinism. The story in *IWINGU-1* relates a story of the mother abandoned by her husband because she birthed children with albinism. In addition, she had to and must still endure insults from almost “everyone” who stigmatises her and her three children. However, the account emphasises how the mother counters social rejection to empower her children and in so doing enables them to exert agency. Thus, the documentary’s title, *I Will Never Give Up on My Albino Children / BORN DIFFERENT*, indicates how the mother accepts, embraces, and empowers her marginalised children regardless of their bodily difference. The children grow up as agentic subjects who express selfhood through talents and ambitions. We learn that the eldest daughter aspires to study medicine, the boy (the second born) excels at

karate, and the youngest girl is a gifted amateur actress, who (in a film) performed the character of a girl with albinism who is always bullied at school. The children enjoy singing and express their understanding of themselves as unique humans through religious hymns (see Figure 6).



**Figure 4: Four of the family's children singing a hymn (*IWNGU-1*)**

*IWNGU-2* also uses the same narrative technique as the first (on and off camera narration, translated interviews and filmed footage) to present the experiences of Shantal, her husband and eight children — four with albinism and four without. The account describes the dilemmas and forms of rejection Shantal endures when she gives birth to children with albinism and refers to cultural narratives that estrange PWA and their families. However, like *IWNGU 1*, this documentary too emphasises the mother's resilience and determination to overcome the hurdles presented by society. Shantal's empowered mothering echoes that of the mother in *IWNGU-1* (as the title signifies). Unlike *IWNGU-1*, however, *IWNGU-2* elaborates on the supportive role of Shantal's husband and medical professionals, who enabled her to exercise her maternal agency, and to ensure the inclusion of her children in a society that repels them.

In *Introduction to Documentary* (2010), the American film theorist, Bill Nichols, discusses types or "modes of documentary film and video" (99). He identifies "six modes of representation that function like sub-genres of the documentary film genre itself: poetic, expository, participatory, observational, reflexive, performative" (99). I find *IWNGU-1* and *IWNGU-2* encompassing aspects of many categories of Nichols' documentary modes, but mostly so an "expository mode" because viewers of the two films can "take [their] cue from the commentary and understand the images as evidence or demonstration for what is said" (107) by the subject depicted in the films, and "participatory mode" for the "[f]ilmmakers make use of the interview to bring different accounts together in a single story", as well as "[t]he voice of the filmmaker emerges from the weave of contributing voices and the material brought in to

support what they say” (122). Thus, it is difficult to classify them as strictly representing a single documentary mode.

In the following section, I focus on how parent-child relationships, particularly mother-child relationships, are represented, notably through third-person voiced narration and interviewee responses (mostly translated from Kinyarwanda into English). I consider how the respective filmmakers attempt to create awareness of the lived experiences of mothers of children with albinism and children with albinism through narration. I use extracts from the narration, along with references to accompanied shots, to demonstrate rhetoric and methods used which depict social and discursive figurations of albinism and what these imply of agency in communal and domestic spheres. To advance this inquiry, I consider how viewers’ comments challenge the widespread social marginalisation of PWA.

#### **4.4.1 Comparing parent-child experiences and relationship.**

One of the key issues that emerges in terms of how the children with albinism are perceived by society and (initially) by their parents is foregrounded in the shared subtitle of the two documentaries, “*BORN DIFFERENT*”. This identity marker alludes not only to the corporeal appearances of the children with albinism who feature in the representations, but also gestures to their disabilities, such as having a sensitive skin, being visually impaired, socially disabled, and the ways in which they perceive themselves, as filmed or narrated. I posit, the short documentary film form of the studied texts, affords agency to voice the social marginalisation of PWA.

In *Signifying Bodies*, Couser suggests the way bodily conditions (such as disability and in this case, albinism) can best be represented in media as he states: “it is desirable for disability to be represented as it is actually experienced by particular human beings” (19). That is, when (in a narrative) disabled people speak for themselves, audiences experience them as narrators and agents who controls their representations. However, Couser adds, “[w]hen those individuals cannot or will not represent themselves, it can be of value to have their lives represented by others. So, when autobiographical representation is not possible, there is great potential benefit in nonautobiographical representation” (*Signifying Bodies* 19). As mentioned, both documentaries selected for discussion straddle modes of autobiographical and biographical narration; they are thus hybrid in form. Despite allowing children with albinism to respond in the first person to the films’ interviewers, the respective families’ experiences are primarily told via the third person voiced narration (the individual mothers’ responses in Kinyarwanda, faded out and translated into English), and filmed footage. Therefore, being represented “by others”

can still accord narrative agency to the non-privileged individuals. The next paragraphs examine the voiced narration (off and on camera narration, some subtitled — interviewed, retold, and translated), and shots from the filmed footage to reveal how they socio-cultural issues discursively undermine the agency and humanity of children with albinism and threaten parent-children relationships as well their corporeal safety.

According to the African critic of non-fiction films, Nwachukwu Frank Ukadike, the “African documentary seeks to interrogate the African experience; the documentary frame might be seen as a transparent window on history, culture, and other issues of resistance” (“African Cinematic Reality” 89). Thus, a documentary provides its subject(s) a space to voice and perform their narratives to the viewers, who also learn about the subjects’ real experiences and contexts. In the discussed documentaries, this agential role is mostly assigned to the narrators/interviewers who tell the stories on and off camera. In *IWNGU-1* the narrator (and supposedly the interviewer) is unnamed, but in *IWINGU-2*, the narrator identifies himself as Prince, and it is through their voices that the viewer learns of cultural and communal myths that undermine sociality, humanity and agency of PWA. For example, although *IWNGU-1* begins with a series of shots featuring individual children with albinism doing house chores, followed by a scene with four children (three with albinism and one without) singing a hymn in Kinyarwanda, the narration in English, first off camera and then on, begins in third person:

In a family of nine children, three were born with albinism. That was the beginning of a painful story—full of bullies. They have been bullied at school, in the neighbourhood and almost everywhere. Their mother was stressed—up and down—because of his [her] children. They told her she produced aliens. She wanted to commit suicide.

This voiced third-person account is then followed by the mother who speaks in Kinyarwanda, subtitled and faded out to continue with what Franco et al. would call the “translation of original speech” (24) in English by the narrating voice which says:

I am a mother of nine children [...]. Three of them have albinism as you can see them. When I delivered a first child, and saw her having albinism. I was not happy for it. To be honest, as long as it was my first time to see[...] an albino. And from then people approached me, and they could tell me bad words, scaring to me, it was a point where I got scared and I thought I brought evil in the world. [...]. Neighbours went away from me. No one could give [me] a glass of water. Even when [they do so], they will break the glass that I have used.

In *The Politics of Storytelling Violence, Transgression and Intersubjectivity* (2002), the literary scholar, Michael Jackson considers that “Storytelling as a vital human strategy for sustaining a sense of agency in the face of disempowering circumstances” (14-15). Such a claim seems true, because enabling others to narrate their story amounts to giving them narrative agency that will enable them to rework their lived past. The two scenarios described above demonstrate how the narrating voice sustains the agency of subjects by telling the audience of the ways in which the subjects (mothers and their children with albinism) are marginalised and banished from society, so by retelling their unfortunate encounters they voice their desire for a better life experience. In a slightly different manner, that kind of narrative agency is echoed in *IWNGU-2* where the English narrator (in third-person voice) introduces the subjects’ ordeals as follows:

No one deserves to be bullied or mistreated in any kind of way. No matter how they look or where they come from. [music fades in and out]. Today, we bring you a story of a woman who gave birth to albino children and her society mistreated her because they thought she was cursed. But that did not make her give up on her children. She fought for them until the end. She is called Shantal. She is a mother of eight. All her eight children are different because four of them are albino. And the other four are just fine, which brings about a lot of discomfort and jealousy among them. Since they all live together, the albinos are always wondering; why were they not born like other.

Imafidon speaks of how African cultures construct PWA as “others” (164) in his study, “Dealing with the other between the ethical and the moral: albinism on the African continent”, According to him, “African communit[ies] establish and promote ontological and normative ideologies that [...] sustain the (ill) treatment of persons with albinism as an other [...based] on superstitions, fear, emotions, religious beliefs, taboos and rituals, and conventions, but hardly on reason” (“Dealing” 164, 172). The validity of this statement is clearly reflected by the above quotations from the films. Despite the problematic diction in *IWNGU-2* which seems to endorse the view that children with albinism are not fine, while implying the dark-pigmented ones as “fine”, viewers clearly notice the role of the translating narrator who switches from first to third-person narrative voice. The narrators’ voices according to Eliana Franco et al., have an enabling capacity: “to portray reality” concerning the subjects for whom they speak for (24, 25). As Valle claims,

[b]e it either a first-person or a third-person omniscient narrator, they all share in various degrees the following features: they are intrusive, all-knowing and overtly in control of the narrative. The implied reader is frequently addressed with questions, pieces of

advice and instructions, thus demanding the reader's attention and participation in the story. (293)

Regarding Valle's assertion, it seems the narrator of each film is one not only critically aware of the suffering of the children with albinism and their mothers' plight, but also voice their own views regarding marginalisation to the viewer. For example, in *IWNGU-1* the first-person narrator, who also translates and tells the mother's first-person account, comments that the children with albinism are regarded as "evil" by society members, and that this is a "painful story — full of bullies". The diction here emphasises discriminatory discourses which undermined the children and their mother's agency. A translated episode of her second born child's experiences exposes that the class teacher once made her a class monitor, but other learners rejected her and questioned: "How come I am their class leader, yet I don't look like them?" The recollection shows how social discrimination impacts on self-perception and agency of PWA. A similar situation is recounted in *IWNGU-2*, where albinism is regarded as for a "curse" by society, which eventually brought emotional and social isolation of children and their relational others.

According to Beti Ellerson's study, "Reflections on Cinema Criticism and African Women", African film makers have a role to play as cultural agents — to inform and enlighten the masses (40). Considering this assertion, filmmakers are thought to offer alternative visions to issues they depict. Therefore, we can read *IWNGU-1* and *IWNGU-2* as "instruments and expressions of learning" (Lara 103). That is, in voicing these ordeals, the translating narrators becomes a means from which the two stories uncover the consequences of irrational beliefs on PWA and this disclosure grants victim agency to the films' subjects. Respective viewers of these narratives learn how myths, rumours, and bias against PWA are discursively constructed in the respective societies/communities where these films are set, and how these denounce individual personhood and agency of children with albinism as well as of their parents. The narrative in *IWNGU-1* reveals how certain beliefs and myths are internalised by the respective parents to notably compromise the mother's agency, i.e., her important role in forging child-parent bonds. The narrator voices the mother's maternal ambivalence that hampers her relationship with her child (with albinism). Her translated voiced account reads: "I was not happy for it. To be honest, as long as it was my first time to seeing an albino" and "when people could come to see my new-borns, they would be scared and asked me how comes that I have delivered the other things again. They never called them children. [...] Some will say I slept with demons, other will say that 'it is genetic', others will say, 'these are evil spirits'". She further recalls: "I had depression, I run mad and felt like committing suicide. [...] I thought may be, there is a special planet for

these people”. In “Labelling albinism: language and discourse surrounding people with albinism in Tanzania”, Brocco writes on language, discourse and albinism. Brocco holds that marginalisation, social exclusion and objectification of persons with albinism begin with the ways the condition is discursively labeled (1154). The mother’s account, cited above, evidences Brocco’s comment, but more importantly, the cultural labeling suggests that the mother and her children are rendered socially unacceptable.

In *IWNGU-2* the third-person narrating voice discloses that when Shantal first gave birth to Beltini, her first child born with albinism, she “had never seen an albino before” or “heard” of “anything like that before in her village”. Although, overcoming some minor challenges, she came to accept her baby after the medical officer told her “an albino”<sup>66</sup> is just a “normal child”, her society did not. When she took “her baby home, all the villagers started laughing at it”, and others “said she had given birth to [a] creature or an alien because none of them had ever seen an albino before”. This discriminating discourse (as is reinforced by a shot re-enacting the villagers laughing at Shantal and her baby, see Figure 3), echoes that of *IWNGU-1*, but more importantly, the medical officer’s comment normalises albinism, and thereby, to cite Valle’s expression, “inform[s] the reader of the narrator’s ideological position in the story” (Valle 294) for he never complies with public views which delegitimise PWA and discursively construct them as alien creatures or things not humans—an insult and abuse to PWA and to their relational others.



**Figure 5: The villagers laughing at Shantal and her baby.**

Nichols argues that a documentary is meant to make viewers “feel on a visceral level more than understand on a conceptual level” about the subjects’ condition (203), as in subjective narration. Thus, as one watches a documentary, one feels concerned with the implied ‘reality’ it re-

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<sup>66</sup> I will clarify the problematic usage of this diction as I conclude this chapter.

presents. The two filmic representations capture the suffering that cannot easily be voiced by mothers of and children with albinism and in so doing, also raise many concerns of these being issues of human rights claims. Life narratives of disabled individuals, Sidonie Smith and Kay Schaffer say, “address the particular needs [...such] as denials of basic human rights”, and quest for “a just social world and of responding to injustice, inequality, and human suffering” (1). This is so because for “rights discourse to become activated, victims need to come forward and testify to their experience” and “[t]heir testimony brings into play, implicitly or explicitly, a rights claim” (Schaffer and Smith 3). As is evident, subjects in the two documentaries “testify” to audiences that PWA are stigmatised, separated, and discursively excluded “from the African community of beings” (Imafidon, “Dealing” 164). Such practices and associated rhetoric in the respective films, not only expose the dehumanising treatment of PWA and their families, but also “provide[...] an account of the lack of justice created by situations of marginalization, oppression or exclusion” (Lara 3). These respective films’ focus on rights serve to insist that viewers reconsider the validity of the dehumanisation the subjects watched face, but what for? Granted, the capacity to talk about the circumstances of victimisation implies that the teller is not a passive victim but a surviving agent (Jackson 14). The “I” perspective foregrounded in the titles of both films, “I Will Never Give Up On My Albino Children”, testifies that the narratives convey first-person accounts and seek to transform, or are transforming, or have transformed circumstances undermining the agency of the subjects – mothers and their children with albinism. Alternatively, voicing sufferings, Schaffer and Smith write, serves as “a chorus of voices demanding response and responsible action” (2) from the public. As with *YouTube* videos (such as these studied here) viewers comments (discussed later) can testify to this assertion.

According to Yaba Badoe, African film makers “[w]ish to make films that speak to our [African] conditions, challenging the existing fictions that misrepresent and distort our [African] realities if they do not completely erase us” (2). Therefore, films, especially in the documentary mode, aim to better the lives of individuals they depict. In this manner, the documentaries explored herein afford their respective subjects’ agency via their depiction of respective empowering narratives that counteract the cultural narratives undermining PWA. These films depict PWA and their respective mothers as subjects who not only “demand recognition [to redefine the] collective understanding of justice and the good life” (Lara 1), but also as agents pursuing justice by countering oppressive strictures that objectify them. In the next paragraphs, further discuss aspects of narration to focus on the way that the two documentaries emphasise aspects of mothering and the supportive role of the respective

mothers of PWA. I demonstrate how the mothers establish intimacy and sociality in the domestic space, resist communal rejection and thereby mitigate conditions for their children, acts which facilitate public sociality and the exercise of agency for the mothers of and their children with albinism.

In “Mothering Children in Africa: Interrogating Single Parenthood in African Literature”, Cecilia Odejobi argues that parents or immediate guardians take centre stage in developing the subjectivity of children. Odejobi says: “The kind of person a child would be is determined by adults’ interest and goals especially by parents and other adults in the family and community” (310). Imafidon too reminds us that societies need “principles that will protect [...] persons with albinism” (“Dealing” 172). Where children are overpowered by discriminating discourses, as in the case of those with albinism, parents or immediate guardians need to protect and empower them so that they can fully exercise their agency. In the two documentaries this role is evident in the mothering ethics of the respective mothers who tell of their attempts to ensure their children’s agency, social acceptance, and positive identities. For example, in *IWNGU-I* viewers are told that the father abandoned his wife and children because he lacked medical and scientific knowledge of the condition of albinism. Like Kama’s father, he believed that his wife is to blame for “cheat[ing]” on him. The situation further worsens because prospective employers refuse to employ him. These employers believe albinism “may cause bad luck to the company.” The mother’s response was: “I kept being strong with perseverance” although “it was too heavy for me.” Her conduct confirms what Olayiwola and Olowonmi describe as a parenting “act [...] characterized by self-reflection that attempts to reclaim and revise indigenous cultural practices” (143), those which dismiss PWA. In her *Toni Morrison and Motherhood: A Politics of the Heart* (2004), O’Reilly speaks of what she terms “motherwork”, an “enterprise concerned specifically with the empowerment of children” (ix). “Motherwork”, O’Reilly adds, is agential for children for it is “concerned with how mothers [...] protect their children, instruct them in how to protect themselves, challenge racism, and, for daughters, the sexism that seeks to harm them” (1). Put simply, “motherwork” implies agential choices that mothering individuals make to promote or protect the agency of children against oppressive systems, and it surfaces in the two films. The second child in *IWNGU-I* recalls an incident at school when she is expelled from school for touching a fellow learner who is repelled by albinism. Knowing that this event claims her daughters’ public agency, the mother confronted the teacher and demanded: “we all have equal rights”. Read against the assertion that stories have “ability to envision normatively – that is, in a critical way – better ways of being in a world

of ‘equality and distinction’” (Lara 6), the mother’s act illuminates her as an agent questing for rights and social agency of PWA.

Like the mother in *IWNGU-1*, in *IWNGU-2* myths about albinism also initially influence Shantal’s own anxiety at giving birth to a girl with albinism, but unlike the uninformed medical personnel Kama encountered when she gave birth, the medical staff who assisted Shantal also told her: “albinos were normal people”. Consequently, Shantal and her “brave husband” were “convinced” “to take it in and call her, [their] child”. The two parents stood together “when all other villagers were neglecting her [the baby girl] and calling her names.” Confirming the child’s value within the domestic space, however, did not immediately facilitate their acceptance by the community. Shantal recalls how her children experienced discrimination at school: they “were always bullied by their fellow students”, and so “they refused to go to school [...] because they felt like they did not fit into their society”. These acts of social exclusion denied them social agency and a sense of belonging. Nevertheless, Shantal’s motherwork code compelled her to secure her children’s right to education. The narrator confirms: “she takes responsibility and talks to the teachers [...] to always help her and keep an eye on her children so that they feel comfortable at school”. The motherwork recounted in both documentaries testifies to Ruddick’s supposition that “[p]reserving the lives of children, is the central constitutive, invariant aim of maternal practice: the commitment to achieving that aim is the constitutive maternal act” (cited in O’Reilly 27). Indeed, although Shantal’s husband’s supportive role is defined in *IWNGU-2*, the testimonies of both mothers in the two documentaries indicate that it is their “constitutive maternal acts” (O’Reilly 27) which endorse the subjecthoods and agency of their respective children in private and public domains.

Carl Plantinga, the American film and media critic, claims that “the illocutionary act characteristic of the typical documentary is to provide veridical, that is, an implicitly truthful, reliable, and/or accurate representation” (“Documentary” 498). The juxtaposition of the filmed footage of the two documentaries, in which the parents and their children feature as interviewees, testify in speech and behaviour how “motherwork” (O’Reilly’s term) is transformative. In *IWNGU-2*, Shantal’s eldest daughter with albinism (Beltini) is briefly interviewed, and the child confirms that her mother’s interventions “has helped them a lot” and, so she studies hard to prove to other learners that PWA can also accomplish success. Imafidon writes, “to fight for the rights of persons with albinism and prove that they are persons [...] we must empower them to care of] their personhood both physically, psychologically and otherwise” (*African Philosophy and the Otherness* 113). This assertion is indicative of enabling “motherwork” as it is depicted in *IWNGU-1* where the narrator reports the mother as saying: “I

always encourage my children to learn and know more; telling them that they are children like anyone else. I try and raise their confidence.” The first-person narration as used here endorses the mother’s resilience to nurture her children’s subjectivities. Indeed, the film’s narrator and the visual footage capture each child’s performing or showing individual talents (including acting, karate, singing and song writing), and the mother testifies “I am their manager at the moment”. These narrative moments confirm that an individual can earn “the capacity to construct meaningful narratives about who she is with relation to others” (Lucas, “The Primacy of Narrative Agency” 126), and that inspiring mothering stimulates social interaction and endorses the aspirations of the children. For example, the eldest daughter with albinism hopes to study medicine to “comfort people, especially these days where we have Covid-19”. Her desire to comfort and cure, to serve others, speaks of her ability to exercise agency and to care for others. The documentary thus depicts the mother and her children as agents who “confront [...] subordinating norms and create [...] new meaning in the face of such norms” (Lucas, “The Primacy of Narrative Agency” 26). In *IWNGU-2* the children seem to be burdened by poverty, judged by the visuals of their poor dressing and housing. Thus, they have little choice to fashion their subjectivities despite their parents’ support. However, they work with other family members in a banana field, and this testifies to the fact that they too are useful, active children.

Plantinga argues that “the documentary filmmaker typically intends the spectator to take what is presented as asserted veridical representations” (“What” 114), and since these documentaries capture the realities regarding the misrepresentation and empowerment of their respective subjects, I would say they do so to assert certain intensions. Pedagogically these documentaries aim to counter deep-rooted cultural or traditional discourses of albinism that developed from ignorance, superstitions, myths, and rumours. Ayisi and Brylla propose that African film makers intend to provide narratives that un-other marginalised identities (126), and Alexie Tcheuyap emphasises that documentarians may educate, inform, and raise the consciousness of spectators regarding what they depict (16). Thus, because online documentaries such as the two studied here can reach a wide audience – across groups – they are a valuable platform to educate and to elicit social commentary. Imafidon says, “very little [had been done ...] to educate not only the persons prejudiced against [PWA], but [PWA] themselves and their caregivers [or community members] who struggle to fulfil their responsibility of care for persons with the condition” (*African Philosophy and the Otherness* 113) and this intensifies discrimination against PWA. In the final sub-section of the chapter, I briefly consider whether the comments made by the viewers of the two films, teach, enlighten, or raise consciousness about albinism, and how these facilitate social acceptance of PWA and enforce their agency.

#### 4.4.2 Discourses of (Dis)empowering PWA in Viewers' Comments

By the time of analysis, *IWNGU-1* had 442,103 views and 786 comments while *IWNGU-2* had 473,425 views and 811 comments. Viewers' comments, says Piotrowski, "expands the textuality of [the commented texts]", and "[form...] a mediated performance that can be studied for productive, discursive flows or disruptive clogs to political expression" (65). Indeed, some comments of *IWNGU-1*'s and *IWNGU-2*'s viewers express their beliefs, sympathy, and appreciation of albinism and PWA. Others support or critique situations presented in the film or other viewers' comments. In "Reclaiming images of women from Africa and the Black Diaspora", Ukadike contends that African films should "construct a paradigm which consists of speaking from within and attempting to compose a rich and varied portrait of the [marginalised Africans] via canonical modification and revisionism" (200). This statement may entail the revisionary role of African film but can be interpreted as a call for documentarians to envisage unique representational methods for depicting African concerns, and for this reason, I consider the sharing of documentaries on *YouTube* as well as viewers' comments as suitable virtual devices for achieving and assessing Ukadike's call. Thus, the next paragraphs analyse some viewer comments as they relate to my focus on sociality and agency of PWA. I consider whether the comments have, citing Imafidon, "facts about albinism that are accurate [or neutral] and up to date" (*African Philosophy and the Otherness* 116) and which might demonstrate whether viewers contest and/or affirm discourses that marginalise PWA. The focus is on how viewers' comments, as a range of community perceptions, provide insights about albinism and PWA, whether these grant agency to PWA and critique discrimination. I argue that viewers' comments, using Schaffer and Smith's words, provide discourses which "affect recourse, mobilize action, forge communities of interest, and enable social change" (3). Andrews comments in "YouTube Queer Communities as Heterotopias: Space, Identity and 'Realness' in Queer South African Vlogs" that viewers (and their comments) are part of online "communities that function as heterotopias, spaces that allow for social and cultural norms to be contested or reversed" (84). My reading of the two films respective viewers commentaries concurs with Andrews' assertion because it is evident that these spaces "provide forums where identity, space and authenticity or 'realness' are invoked and reimagined in ways that speak back to the limitations or oppressions experienced [by marginalised identities] in offline spaces" (84). I contend that viewers' comments are agentic because comments (de)construct discourses that support ostracization of PWA and grant them voice and ontological agency.

The societies depicted in the two short documentaries construct PWA's identities as inhuman and devastating. Such narratives are among those which might motivate exclusion of PWA

from the society and inhibit them from living fully. However, as Sidonie Smith and Kay Schaffer observe in *Human Rights and Narrated Lives: The Ethics of Recognition* (2004), once a personal story of marginalisation is shared, the shared story can “motivate the rights movement” upsurge (15). This assertion manifests when viewers’ comments of the two documentaries discursively celebrate albinism as a valid identity by alluding to religious and scientific explanations of albinism to claim the right of social inclusion of PWA. Comments<sup>67</sup> on *IWNGU-1*’s state:

1. Lontia Banda: ... why Africans always have to associate witchcraft with how different someone looks and I’ve always been embarrassed about how my country does this as well. We are all fearfully and wonderfully made by the hand of God”.
2. Jessica Richards: Why can't we just love and accept each other these children are beautiful how can a genetic condition make you alien may God bless and keep them safe.
3. Alyson Jones: Let us not discriminate, God made all colour and race. Watchin from Jamaica

In *IWNGU-2*, some of the comments read:

4. Tess: So much stupidity and ignorance! The only thing an albino has is lack of melamine and most do suffer from poor vision, sun glasses would help. The parents had these kids cause both carry the gene for albinism, could those shooting the video explain to this family and their neighbors pls!!!!.
5. Maria Patino: No matter the color of your Skin, Ethnicity, or Gender--we are all equal.....Love, Respect and prayer from Philippines...
6. Lishen Ann's: OMG how can they called it as a curse. It's a blessing (God's gift) A kind of uniqueness which everyone Admires I love this kind of uniqueness.
7. Esin Esin: They're so beautiful, this is Eve genes thanks to God they are fine they work, they walk they do everything I like that children.

Piotrowski argues that “the ability to [...] struggle for justice” is something “extending beyond national boundaries” (67). Smith and Schaffer would describe this combined struggle as “networks and informal meshworks of advocacy—the dense and nonhierarchical flows of connections among groups and peoples working on behalf of human rights that transcend national boundaries” (15), and whose discourse, citing Imafidon, is “reconstructive”, for it might “correct the wrong notions about albinism in African societies” (*African Philosophy and the Otherness* 111, 119). Indeed, the comments above motivate one to consider the two films’

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<sup>67</sup> Comments are used in their original format and style to maintain authenticity.

viewers as heterotopic agents. As Andrews avers, through *YouTube* comment function, viewers “can create and enter community spaces in online realms that are hybrids of real and virtual spaces, and where they can find solidarity and connection in ways that might not be possible in offline social realms” (86). I concur, *YouTube* comments is an enabling virtual space which allows transnational viewers (from Jamaica or the Philippines or anonymous places) to debate issues concerning, in this case, PWA and albinism. Interestingly, the debate rearticulates who PWA are and what albinism is and thereby attempt to rebuff the social isolation of PWA. For example, *comment 3* is a plea: to “not discriminate” against individuals because of their skin colour, because all humans (including PWA) are made by God, the very same idea held in *comments 1, 5 6, 7*. In endorsing the view that albinism is Godly, all these comments not only call other viewers to socially accept albinism and PWA, but also identify with the viewer who calls for love, respect and appreciation of albinism, thereby implying that albinism is a form of “human plurality” (Arendt’s term). This perspective is highlighted when *comment 6* insists: albinism is a “[a] kind of uniqueness which everyone Admires. I love this kind of uniqueness”. Moreover, *comments 2 and 4* enlighteningly resist the reduction of PWA as creature or a curse by clarifying that albinism is a genetic condition. The rhetoric of association conveyed in *comment 7*, which refers to the “Eve gene”, endorses the view that humans, including PWA, are all matrilineally related. This relationality is further underpinned in comments that voice admiration and love of albinism as a form of “uniqueness” (for example in *comment 6*), and in these ways the viewers’ comment space calls for the inclusion of PWA in human society. We can also read the above comments as a kind of critique against the marginalisation of PWA. According to Wendy Brown, people “critique [...] to set the times right again by discerning and repairing a tear in justice” (6). As critiques, the comments are utterances seeking to expand the conception of social justice, and to this end, the views embedded in the above comments are presented as counterattacks to the estrangement and marginalisation of PWA depicted in the two films. They thus cement Andrews’ assertion that *YouTube* film viewers’ comments constitute agentic communities that “challenge the assumptions of social power hierarchies” (88). The two documentaries analysed here demonstrate the social reality of marginalised subjects with albinism and viewers comments facilitate a platform to voice disassociation from discriminative discourses in defence of and acceptance of PWA.

Kristin Pischaske argues, in “Colour Adjustment: Race and Representation in Post-apartheid South African Documentary”, that a documentary narrative shared on *YouTube* “may [...] convince some perpetrators of social injustices to amend their ways” (57). However, this may not always be the case because, as Schaffer and Smith assert: “There is always the possibility,

however, that [some] stories will not find audiences willing to listen or that audiences will ignore or interpret their stories unsympathetically” (6). This unsympathetic reaction is depicted in *IWNGU-1* viewers’ comments, where Joe Jackson comments: “I think this woman is lying because albinism has been part of Africa for so long. I grew up with many of them so why are you guys talking as if as is the first albino in Africa”. By rendering the film’s subject as “lying”, the term not only underplays the exclusion of PWA in Africa, but also negates victim agency of the film’s subjects. Thanks to the fact that the *YouTube* comment function is a polyvocal space — it allows the “intercutting” of voices, or “contradictory assemblage” of narratives (Schaffer and Smith 80), akin to politics of equality. In response to Joe Jackson’s comment, some viewers voice what Andrews describes as “support for the experiences of others [the undergoer of the experience narrated in the films]” (Andrews 84), and “attempt [...] to forge a space for the recognition and celebration of their [PWA’s] lives” (85). Such recognition and support, some viewers comments reveal, grant agency to PWA, as is demonstrated in the following comment:

Siah Young: @Joe Jackson Albinism has existed all over the world for so long, but this is their story...And if you grew up with many of them, then you know first hand that they are bullied and ostracized, so why are you pretending that it's all love in Africa!

Maneno'sTV: @Joe Jackson not every counties [country] accept us (with albinism) and not every counties [country] reject us, it's also dependent how many we are in that particular country, countries like Congo, Tanzania and Burundi, since 2000 we've increased in numbers and they started to believe we're normal [...].

Here, Siah Young’s use of “us” is significant. The viewer responds as a subject with albinism, asking and countering “why are you pretending that it's all love in Africa [while PWA in African are being] “bullied and ostracized?”. In this way the viewer claims agency for the self and other PWA. In addition, Maneno'sTV’s comment, “not every counties [country] accept us (with albinism)” can be read as a call for global social justice, since it unequivocally mentions that PWA are marginalised, and implicitly demands these people’s recognition and inclusion.

To conclude my discussion, I suggest that the documentaries explored here, which rely on autobiographical as well as biographical modes of narration and comments, demonstrate the capacity to voice social marginalisation of PWA. Additionally, they offer representation that may transform discourses of social exclusion of PWA by alluding to empowering mothering. Their respective viewers’ comments also breed what Imafidon could describe as a

“reconstructive [...] awareness” (*African Philosophy and the Otherness* 113), an awareness that is essential for whoever views the documentaries and read fellow viewers’ comments to understand the ill-treatment of PWA. However, (without essentialising), the translating third-person narrations used in the two films have limitations and flaws in giving narrative agency and conveying embodied subjectivities of the films’ respective subjects, more so than for example autobiographical accounts which predominantly use first-person narration. As Couser explains in “Body Language: Illness, Disability, and Life Writing”, an autobiographical account greatly enables a subject to “[enact the...] message: there’s a person here, capable of self-understanding and self-expression” (5), and who despite his/her bodily condition acts in or is the subject and not the object of the story. By contrast, embodiments, and experiences of PWA in the documentaries I studied are narrated and mediated dominantly by the narrator whose voice somehow subjugates the image, voice and subjecthood of the children with albinism. For example, the two documentaries’ agendas, which is to rework the social othering of subjects with albinism, are marred by the discourse used by their respective third-person narrators. However, as Nichols argues, the voice-over commentary “has the capacity to judge actions in the historical world without being caught up in them” (107). Regarding Nichols’ claim, it can be presupposed that filmmakers, especially of narratives, who seek to empower marginalised subjects, must interpret the world and the subjects they depict in terms that avoid demeaning connotations. Contrary to this, the respective voices of narrators/interviewers of *IWNGU-1* and *IWNGU-2* mar their narration when they frequently refer to children with albinism as “albinos” and those without as “normal”. In *IWNGU-1*, the narrator not only refers to children without albinism as “fine” but also “beautiful”. The use of the term “albino” is derogatory for it “equate[s] the person to her most visible aspect: albinism [...which is] is contrary to global efforts to advance the dignity of *all* persons”.<sup>68</sup> Moreover, while the narrators’ use of these terms might represent a faithful translation of how PWA are referred to in the mothers’ narratives, at times, and perhaps unknowingly, seem to encourage the othering of PWA.

#### 4. 5 Conclusion

This chapter explored modes of representation in two autobiographical written accounts and two short documentaries to demonstrate how sociality (re)configures agency and stereotypes which undermine albinism and persons with the condition. By exploring these different life narrative forms, the chapter aimed to broaden the range and contribute to the scope of literary-cultural scholarship on albinism in its focus on (self)representation of lived experiences

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<sup>68</sup> See “ALBINO” VS “PERSON WITH ALBINISM (PWA)”  
<https://www.underthesamesun.com/sites/default/files/WHY%20WE%20PREFER%20THE%20TERM%20PERSON%20WITH%20ALBINISM.pdf>

albinism and commentary by real, historically verifiable viewers. The discussions submit that positive social relationships cultivate agency in PWA. Also, through exercising their agency, subjects in the respective narratives deflate stereotypes associated with albinism. I thus describe the written autobiographical narratives I explored as having, citing Couser, the “potential to counter stigmatizing or patronizing portrayals of disability”, and as “a medium in which people may have a high degree of control over their own images” (*Signifying Bodies* 31). That is, through self-representation subjects vindicate their negated humanity. For example, the autobiographical “I” in Kama’s and Bongelo’s respective narratives exerts these narrating subjects firstly as human and secondly as agents who contest the negative figurations of albinism that they encounter. By contrast, although respective English translations of the narratives convey the discourses of social marginalisation of PWA in as far as this hampers subjectivity and agency of children with albinism and their respective mothers, the mere fact of relating images according to the discursive understanding of the narrators, results in the subjects in the two films losing direct control over their images as projected in the narration. Even so, the documentaries’ representation of empowering mothering might enable social agency of PWA. Furthermore, *YouTube* comments provide a site where viewers educate among themselves about albinism, critique social exclusion by voicing rights claims for the inclusion of PWA and accord them human agency.

## CHAPTER FIVE

### CONCLUSION: TEXTUAL (RE)CONFIGURATIONS OF ALBINISM AND UNMINED POTENTIALS

Laura leant over and said, “Melanin is the dark colouring gene that protects those normal folks from ultraviolet rays. We don’t have them, so we’re pale and over exposed.”

“Stop using normal. Say black.”

(Halim, “The Albino Outreach”, 2019)<sup>69</sup>

This multi-disciplinary and cross-cultural research interrogated representations of characters and subjects with albinism in eight literary and cultural texts from East and Southern Africa. The study explored how contemporary representations of characters/subjects with albinism challenge or support stereotypical perceptions of PWA as “other” (Imafidon, *African Philosophy and the Otherness* 111), vulnerable and/or lacking in agency. The study argued that fictional and life narratives (auto/biographical writings and short documentaries) are sites where issues of agency of characters and subjects with albinism are (re)constructed, and that through representations, writers, life narrators and film makers (de)construct stereotypes, myths and perspectives which might negatively or inaccurately describe PWA and their condition. Briefly, all the texts studied in the thesis demonstrate (disturbingly so) that marginalising discourses against PWA are evident in the diversity of contexts and cultures of the studied regions (East and Southern Africa) and that such perceptions exist across national, cultural, and traditional borders. More importantly, this study demonstrated that writers of fiction, life narrators and film makers differ in their narrative methods and the extent to which these are employed to question and represent stereotypical perceptions of albinism, as well as differing in their depiction of the possibilities of agency and personhood for characters or subjects with albinism. The conclusion drawn from this study resonates with Jeffreys’ argument of the (dis)enabling possibilities of the body-cultural “seam” (see the epigram in Chapter One) and indicates that as much as cultural narratives can falsely authenticate pigeon-holing, oppression, and stigmatisation of disabled or marginalised bodies, they can also positively (re)present such bodies. This claim is rendered valid, because, although some of the stories or accounts analysed exhibit instances of marginalisation, they all hold reconstructive and educational potential regarding discourses that undermine albinism and PWA.

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<sup>69</sup> See Ola W Halim. “The Albino Outreach Worldwide: A semi-autobiographical story about albinism and identity in Nigeria”, <https://kalaharireview.com/the-albino-outreach-worldwide-e09c52fcc72c>

Imafidon discusses media as an example of an “effective [reconstructive] tool” which can “play a key role in combating the prejudice against persons with albinism” (*African Philosophy and the Otherness* 19). He calls for the “airing of programs and writing about things that correct the wrong notions about albinism in African societies” (Imafidon, *African Philosophy and the Otherness* 119). Although my study identified the diverse ways in which the vulnerability of characters or subjects with albinism is represented in the studied texts, it also revealed the reconstructive potential of each of these narratives to impact on the identity and agency of PWA. The narratives I interrogated verify that (self)representations “about albinism in African societies”, from inside the chosen region, not only bring into focus social realities and cultural truisms regarding albinism and PWA but represent how stereotypes and agency of characters and subjects with albinism are negotiated, challenged, and (dis)enabled.

In Chapter One I expounded the main inquiry of this thesis (reiterated in the opening paragraph of this chapter) and its focus on agency. I motivated my interest in literary representation of subjects and characters with albinism in my autoethnographic reflection and extrapolated how these experiences brought me to this academic research. The chapter further elaborated that this research deployed a cross-disciplinary theoretical approach for it drew primarily on disability studies, gender studies, African philosophy, narrative theory, and life narrative studies to examine how agency of characters and subjects with albinism, as well as stereotypes associated with the condition, are (self) (re)presented in the inquired narratives.

I have summarised my findings of each analytical chapter in the conclusion of each, but briefly recap key ideas here. The first of the three analytical chapters (Chapter Two) focused on two children’s novellas by Nahida Esmail and Elias Mutani. The chapter explored how the texts respectively narrate agency of child characters with albinism to demonstrate the ways individuals and charitable efforts can shape each character with albinism’s sociality and agency (i.e., how textual representations enables or restrain agency of children characters with albinism. Drawing from Butler et al.’s notion of vulnerability, the chapter argued that Esmail’s and Mutani’s novellas imagine albinism as a condition which renders the child characters vulnerable. Consequently, the characters with albinism struggle to exercise personal and social agency because they are frequently mistreated — verbally and physically. Hence, both novellas imply that children with albinism are overwhelmed by socio-cultural and economic factors which inhibit agency, and that communal or organisational humanitarian support is needed to overcome conditions that endanger the child character’s very existence. With recourse to Barker’s ideas on representations of children with disabilities, Garland-Thomson’s notion of the misfit, and African philosophical views of *ubuntu*, I interpreted these texts as reflecting on

the need for the child protagonist to be shielded from hostile attitudes and also the need for a proxy agent who could intercede in vulnerable living conditions that robbed the characters of agency. In questing whether the narrative techniques employed in these two novellas grant characters with albinism's agency, I examined the recurring motif of altruism, the use of types of narrative perspectives and the juxtaposed patterning of characters with and without albinism. Regarding the narrative perspectives, I established that the "omniscient-narrative perspective" and "the first-narrative perspective" (as deployed in Mutani's and Esmail's narratives respectively) bear conflicting results in (re)configuring agency of child characters with albinism. In Mutani's text, the omniscient narrator seems to narrate from a decidedly ideological angle which skews towards a more favourable portrayal of the character without albinism, Joan. Consequently, Jasiri, the character with albinism appears less agentic and incapable of acting for the self – a passive figure in need of Joan's succour. Contrarily, Esmail's use of first-person narration, from Tatu's point of views, grants this character (with albinism) speaking agency to voice her appeals to her audiences (characters and readers alike) and increased agency therefore influences her life and selfhood positively. Moreover, I have argued that proxy agents (in the form of altruistic characters) can have diverse forms of impact on the agency of the child protagonists with albinism. Mutani's text teaches us that the inconsiderate proxy agent (Joan) with her domineering character may undermine the agency and interests of the protected child with albinism (Jasiri) whom she labours to protect. By contrast, the considerate altruistic characters who embrace *ubuntu* virtues, for example Mama Mkubwa, Sister Julianne and Brother Karimu, in Esmail's novella care for the wellbeing and the flourishing of children with albinism. My discussion of the two texts reveals, altruism can be agentic to educate and install humanitarian values in child readers even when a character without albinism is more favourably portrayed. In Esmail's text, altruistic characters empower Tatu to fight for her life by enabling her with a secure environment which grants her agency, the confidence to act personally and socially. Although altruism ensures the protection and the survival of Jasiri in Mutani's text, the narrative patterning of characters with and without albinism exposes the character with albinism as though he is debilitated, but the pedagogical value of the text, regarding albinism, remains valuable. Altruism thus, unexpectedly, elevates (by giving more agency) the character without albinism to decide (both friendly and in a forceful manner) the fate of a character with albinism. It is therefore important to note, Mutani's techniques of representations can either heighten or challenge (mis)representations of each child character with albinism and this might impact on the perception of the child reader. However, despite Mutani's problematic portrayal of the child protagonist without albinism as dominating the one with albinism, both novellas appear to grant the ability to voice agency and

to offer depictions that resist discourses that undermine children with albinism. This is also the case evident in representations of the “albinotic body” in the novels analysed in Chapter Three.

Chapter Three traced how Petina Gappah’s *The Book of Memory* and Unathi Magubeni’s *Nwelezenga: The Star Child* deploy multi-layered intertexts to portray the socio-cultural (historical) perceptions of albinism in the worlds reflected by each of these novels. Here, the focus was to examine whether intertexts work as speech acts (with illocutionary agency) to transform toxic conceptions of albinism and (re)cultivate public agency and acceptance of albinism and characters with albinism, and by implication people living with the condition. The chapter noted that intertextuality in these texts “emerg[es] in diverse forms as direct quotation, citation, allusion, echo, reference, imitation, collage, parody, pastiche,” and “literary conventions” (Zengin 300), and that these infuse the two novels with contesting or ambiguous socio-cultural ideas about albinism. Some intertexts, the chapter discovered, are agentic utterances which can (dis)enable discourses which undermine the public agency and acceptance of characters with albinism in the respective novels. That is, intertextual insertions in Gappah’s and Magubeni’s texts grant the novels’ respective narrators (with albinism) inconsistent agentic capacities to reassign public agency and upliftment of characters with albinism, and by extension, albinism and PWA. I have demonstrated, both novels’ references to historical or religious myths are agentic and humanise characters with albinism to portray them as Godly creations. Such an identity not only increases public agency for characters with albinism and reader understanding of the plights suffered by characters with albinism, but by extension, installs acceptance of people with albinism in actual life. However, types of agencies wrought by intertexts (such as Gappah’s deployment of *ngozi* and Magubeni’s allusion to traditional healing practices), I have noted, refract (or blur) the respective texts’ (re)articulations of realities about the condition of albinism. These intertexts create (in the two texts) a crisis of representation, or “Aesthetic nervousness”, as Quayson would term such a crisis. Gappah’s deployment of intertexts in her novel, I argued, does not fully neutralise the myth that a child with albinism is born of parents who are cursed. In Magubani’s novel, the referred intertexts appear to reassign a disparaging identity to the protagonist with albinism, reinforcing a view that PWA are spiritually elevated or ‘other’. Given that these novels might also be read by audiences who are un- or misinformed about albinism, slanted portrayals of albinism and characters with albinism might trouble creative agendas, aimed to empower people with the condition, and public understanding of albinism and behaviour towards PWA. These novels, I argued, are examples of how fictional representations of somatic conditions are rendered problematic and inconsistent for they are caught in the trap where social construction of somatic

conditions engenders textual representation of albinism and PWA. Such portrayals then become a means through which the meaning of albinism is passed to their respective readers; a problematic representation evident also in Mutani's novella.

In Chapter Four, I interrogated written and short documentary accounts of actual subjects living with albinism. The chapter aimed to show how life narratives about sociality, or the lack thereof, speak of agency of actual PWA. To explore themes and issues related with sociality, the chapter drew on Lucas's notion of "ontological agency", the term she develops in conversation with Arendt's ideas, to study how conditions such as intimate relationships (friendly and familial), loneliness, isolation, and exclusion can affect subjects who strive to exert themselves as unique agents (Lucas, "Loneliness and Appearance" 714). Imafidon's postulations on how African ontological views present existential challenges to people with disability (albinism in particular), and how these impact on PWA's social agency, have been particularly instructive for my analysis in this chapter. Furthermore, the chapter also reflected on the assertion that African documentarians are "cultural agents" and "producers" (Ellerson "African" 224), to examine whether *YouTube* documentaries and viewers' comments (de)construct normative ideologies which 'other' PWA. Focussing on the autobiographical "I" narration used in Kama's and Bongelo's written accounts, I explored how their respective personal narrations convey an understanding of their social and personal experiences which influenced their respective ontological agency. The "I" narration clearly grants textual agency to the narrating subjects who voice their lived experiences and reveal aspects of individual subjectivity. In this way, the "I" perspective enables each narrating subject to exercise agency and to 'appear' as "unique" bodies and identities before the reader within their narrated worlds (Lucas, "Loneliness and Appearance" 716). For example, Kama's autobiographical "I" is an agentic device used to voice how her agency as a subject with albinism was initially impaired by the lack of social and familial support, which resulted in loneliness and isolation. Through the "I" perspective, Kama's account further narrates how she gradually developed social and personal agency. For instance, through practices of "empowered mothering" (Haratyan 43), I argued, Kama acts agentic to be recognised not only as a mother but as an agent who speaks out against discriminating discourses that marginalise subjects with albinism and their relational others. My reading of Bongelo's written account shows empowering personal and social relationships are at the core of his agentic development. Bongelo's first-person narration unfolds to affirm that conducive relationships enabled him to exert his "elementary confidence" (Arendt, *The Origins* 477). By being a narrator, Bongelo confirms his capacity to display his agential uniqueness by appearing, acting, and speaking before others (readers and) subjects within the

world of his personal account. Friendly companionship therefore provided Bongelo with the confidence to navigate his identity. In examining the two short films, I continued the chapter's focus on aspects of narration. Here, I considered the shifts between first- and third-person narration in the two auto/biographical narratives-voice-over, narrators and subjects interviewed. I analysed how disclosure-voicing-of social factors (de)legitimize PWA, as well as the significant role of the mothers of the children with albinism, featured in the documentaries, and how supportive mothering installed agency in the children and in the mothers. In addition, I discussed the ways *YouTube* viewers' comments, as "heterotopias" (Andrews), configure agency of and for subjects with albinism. The section argued that the translating first-person narrators of the respective films enable the viewers to enter the world of the interviewed subjects they speak for despite limitations posed by translation and retelling in "speaking-on behalf" of the interviewees. Being spoken for limits personal voicing of subjects with albinism or their parents (represented in the two film) and a chance to tell viewers that they are people who "seek to represent their own bodies on their own terms" and that "their narratives may seek to reduce their vulnerability to pre-inscribed narrative" (Couser, *Signifying* 12, 18). Even so, although in some instances translated or voiced-over narration falls short in the use of language which objectifies the subject they speak for, the narration still endorses agency of the biographical subjects. Furthermore, I discussed how the mothers of the children with albinism grant agency to their children. Both documentaries draw attention to cultural and social discourses, such rumours, and myths, which render children with albinism as socially unwanted. The respective auto/biographical narrations show that supportive mothering is empowering for PWA and confront normative ideologies that sanction the social exclusion of children with albinism (and their families). My exploration of viewers' comments further discussed how rhetoric used in these comments counter social othering of PWA. The inquiry noted, viewers perspectives of albinism (as depicted in their comments) can contribute to alter social, cultural views of the condition online, these comments might affect changed perceptions off-line, establishing a network of voicing that give agency to PWA and an understanding of albinism.

Imafidon states that lived experience of PWA can reveal how PWA empower themselves, are empowered by others, and how this in turn imparts knowledge of albinism as a condition (123). Such is the potential of narrative in diverse forms and genres; the narratives I explored here have rendered Imafidon's claim especially valid. However, it is important to note that in arguing for the representation of marginalised individuals such as PWA, Lipenga and Ngwira remark that "an objection could be levelled against [...] works of the imagination, and on the grounds

that they are not reality” (1485). While this may not always be the case, such criticism can also be directed at other genres or mediums, because (knowingly or unknowingly) life narrators/authors/producers can infuse their tales with their internalised assumptions of the issues they present. My discussion of the written and filmic auto/biographical accounts propose that non-fiction narratives carry a level of authenticity, especially when told from the perspective of the experiencing subject with albinism, thereby allowing convincing agentic expression. This said, I remain cognisant of the fact that each genre/text/form is limited in what it can do. As Catharine Abell argues, in “Genre, Interpretation and Evaluation”, “a work’s genre can affect how we interpret its representationally relevant features”, and that “[a] given phrase may require either literal or metaphorical interpretation, depending on the genre of the work in which it occurs” (26). Furthermore, some literary and cultural “[w]orks do not explicitly represent all aspects of their content. Some must instead be inferred [based on] what they explicitly represent” (Abell 27). Genres thus have limitations and a work’s genre invites certain interpretations or expectations according to which an audience/reader might be expected to infer its meaning and relevance. Supposedly, it is for this reason that Lipenga and Ngwira have acknowledged, in arguing for the voice of albinism, that we can “give credits to autobiographical writing” while reminding that such recognition should not “in a way, limit [...] opportunities for learning” (1485). For Imafidon, media provide opportunities for learning and (de)construction of discourses which confound albinism and PWA when they “[... expose] sectors and aspects of society that continuously encourage the harming and stigmatisation of [PWA]” (*African Philosophy and the Otherness* 119). In view of my study, representations of PWA in a variety of media, genre or form not only expose the ill-treatment of PWA, but also uniquely challenge and possibly provide alternative insights to undo them. It is then tricky to conclude that certain genres (and not others) propagate misrepresentations of persons with albinism because misrepresentations and/or positive significations of albinism or any form of marginality may happen in narratives across genres. Various (re)presentational platforms such as films and beauty pageants, Imafidon clarifies, play contradicting roles in empowering PWA. While beauty pageants in Africa (founded by PWA themselves), according to Imafidon, beautify and thereby objectify PWA, the film industry has wreaked even more destruction. Notably in cases such as Nollywood productions, PWA are represented as “evil” (*African Philosophy and the Otherness* 119). I also argued in my discussion of the two short documentaries that such is also the case in the language used by the translating narrators who use expression such as “albino” and “normal” or “beautiful” to describe or categorise persons with and without albinism, respectively. I contend that the findings of this study demonstrate the ways fiction (novellas and novels) and life narratives (auto/biographical accounts — written

and filmic) contribute to the understanding of the social reality of albinism. Thus, studying diverse forms, genres and/or mediums of representations can diversify our understanding of agency of characters or subjects with albinism and of the condition of albinism.

In line with this assertion, I agree with Suzan Wells' supposition that "genres [can be thought of] as territories with multiple points of contact and nodes of exchange" (114). However, I remain cognisant of the fact that a distinct genre can (in various situations) "move differing audiences [...] to produce distinct effects" (Aristotle as cited in Wells 114). Furthermore, I see fiction or life narratives, written or produced from the experience of the culture of the character or people it (re)presents, as being crucial to convey an understanding of conditions from within — of living with albinism in a specific socio-cultural context. Even so, albinism is of course not only a condition significant to Africa but a reality which warrants transnational research on the topic. However, given the history and ongoing experiences of albinism in Africa, "punctuated with killing, maltreatment, dismembering, and stigmatisation" (Imafidon, *African Philosophy and the Otherness* 3), it is vital to represent and study the condition from within. Therefore, while this study explored fiction and life narratives of albinism produced by Africans from the studied region, it also acknowledges that the experience of Africans with albinism have been represented by writers and producers from other African regions and from outside of Africa, and these require scholarly attention. What follows therefore is a reflection on the range of texts and possibilities for future research, but first I comment on some of the challenges I experienced during this study, and how these shaped my ideas regarding future research.

One of the problems I encountered on my research journey relates to the sourcing of materials, notably texts that might have been beneficial for the cross-genre and regional focus of my study.<sup>70</sup> For example, in Chapter One, I mentioned how I struggled to source full-feature documentaries by Lupita Nyong'o's *In my Genes* (2009). Such was also the case regarding the anthology: *Excuse my Colour: Stories of People Living with Albinism* (2019), edited by Nathi Zuma, and fictional works by, for example, Rutendo Tavengerwei, *The Colours That Blind* (2019), as well as Goro Wa Kamau's *Ghost and The Fortune Hunters* (2016). I return to this point when I discuss potential avenues for future research. Moreover, when I first embarked on this research, I assumed that issues related to agency and stereotypes confounding characters and subjects with albinism could primarily be dealt with within the framework of disability and vulnerability studies. However, the complexities of albinism, which nestles at the nexus of so many issues (e.g.: belief systems, race, class, gender, ethnicity), called for a broader multi-

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<sup>70</sup> The struggle to source germane material was intensified by Covid-19 pandemic which restricted access to online and physical (library) research platforms, especially when I was at home in Tanzania.

disciplinary methodology which in turn opened a vast scope of approaches from which I necessarily had to select to site my focus on agency. My agency-oriented study was consequently guided by thematic similarities, particularly vulnerability and stereotypes associated with albinism and its impact on agency. Most of the theories utilised by this study were complementary to my focus, as the analytical chapters have demonstrated.

As I mentioned earlier, the initial cross-genre focus of this study also proved challenging given the difficulties to source texts that might have been crucial for this purpose from within the regions I intended to explore. However, such a challenge drove home an awareness of the unmined territory and possibilities for studying literary and cultural representations of albinism and characters or subjects with albinism by writers/producers from inside and outside Africa. I briefly consider various directions in the penultimate paragraph.

African characters with albinism feature in many youth novels and novels for adult readers by writers who live outside Africa, and most of these representations are the result of research conducted on albinism by the individual writers while on excursions to various African regions, for example: *Then She was Born* (2015) by Italian author Cristiano Gentili (Italian), *Golden Boy* (2014) by Tara Sullivan and *Unexpected Destiny: A Story of Albinism* (2014) by Pat Estes, both Americans. Furthermore, the experience of Africans with albinism is also a topic in comic and transmedia by American writers and creators. This media category includes works such as *Flesh of White* (2015), a tale written and illustrated by Erica Heflin and Amanda Rachels, and *Zeru* (2013), a transmedia narrative (in the form of a graphic novel and an online documentary), produced by Dan Wechsler. African writers/artists from outside the studied region, also take albinism in East Africa as topic of representation, for example, the comic *Under the Sun* (2019) by Austine Osas and Abiodun Awodele from Nigeria. I mentioned the difficulty of timeously sourcing texts from Africa that deal with albinism in the regions I studied. There are also narratives from regions other than those targeted by this study that have albinism in Africa as subject. The latter category includes, for example, Nigerian writer, Nnedi Okorafor's speculative fiction series, *Akata Witch* (2011, 2017, 2018) and Nollywood productions. More so, poetry, lyrics, artworks – by and of PWA – remain un(der)explored, as is the case with short stories and life narrative anthologies such as *Excuse my Colour: Stories of People Living with Albinism* (2019),<sup>71</sup> edited by Nathi Zuma. Similarly, cultural events or mediums such as beauty pageants, television talk shows/interviews/series, and artwork or photographic collections/exhibitions such as Hugo Pieter's *LOOKING ASIDE* (2006) and Farah Ahamed's

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<sup>71</sup> I obtained a copy of this anthology during the final stage of writing this thesis.

*Pride and Prejudice: The Gerald Kraak Anthology African Perspectives on Gender, Social Justice and Sexuality* (2017), offer pathways for further research.

The scope of texts and possibilities are ever expanding, but the need for literary-cultural (self)representation and scholarly investigation of albinism is endless and a crucial ethical call. To this task, this study aimed to contribute and has done so, notably in its focus on configurations of agency in representations of characters and subjects with albinism. My study explored various techniques of representations from diverse genres (of literary and cultural texts produced by individuals from within Africa and set in African contexts). It has demonstrated that in the narratives explored, agency of subjects and characters with albinism is (re)shaped by the respective narrative techniques used, such as modes of narration or narrative perspective, intertextuality, ambiguity, characterisation, and themes or issues depicted in relations to agency such as vulnerability, altruism, sociality, as well as social-cultural and historical perceptions regarding the condition of albinism in the contexts which the writers write from or about. We thus have endless methods and possibilities in which agency of characters with albinism can be represented given the said dictating factors, the effectiveness of media used and individual authors' understanding of albinism. Thus, I suggest that an examination of representations of African subjects and characters with albinism produced from within and outside Africa might add new insights to the existing scope of literary-cultural criticism.

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