

‘Being different’: realities of life experiences as constructed
by persons with albinism in Nigeria

Thesis submitted in accordance with the requirements of the
University of Chester for the Degree of Doctor of Philosophy

by

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Declaration

The material being presented for examination is my own work and has not been submitted for an award of this or another HEI except in minor particulars which are explicitly noted in the body of the thesis. Where research pertaining to the thesis was undertaken collaboratively, the nature and extent of my individual contribution has been made explicit.

Signature:  :

Date: 13/08/2019

Tables of contents

Declaration	2
Tables of contents.....	3
List of Figures.....	6
List of Tables	7
Acknowledgements.....	8
Conference papers.....	9
Abstract	10
Overview and structure of the thesis	11
Chapter 1	14
1.1 Introduction.....	14
1.2 Moral philosophy	19
1.3 Research philosophy.....	26
1.3.1 Aligning with Charmaz’s Constructivist Grounded Theory	30
1.4 Research aim and objectives	35
1.5 Summary	35
Chapter 2: Literature review	36
2.1 Introduction.....	36
2.2 Albinism: definition and manifestations.....	37
2.3 Origins of social identity for Persons with Albinism	40
2.3.1 A descriptive historical perspective	40
2.3.2 The role of symbolic interaction in the social misidentification of persons with albinism.....	47
2.3.3 Labelling as a mechanism for albinism stigma	48
2.4 Social construction of albinism across Africa.....	54
2.4.1 Impact of the albinism stigma on marital and household wellbeing	55
2.4.2 Impact of the albinism stigma on education.....	57
2.4.3 Impact of the albinism stigma on employment opportunities	58
2.4.4 Impact of the albinism stigma on health and wellbeing.....	59
2.5 Influence of the film industry on albinism stereotypes and social identity for PWA ...	60
2.5.1 Hollywood and Western representation of albinism and PWA.....	62
2.5.2 Nollywood representation of albinism and PWA	67
2.6 Albinism as a disability	72
2.7 International and national responses to the plight of PWA	76
2.7.1 The United Nations approach.....	76
2.7.2 The Response of the Nigerian Government	78
2.7.3 Discrimination Against Persons with Disabilities (Prohibition) Act, 2018	82
2.8 Summary	84
Chapter 3: Methodology	86
3.1 Introduction.....	86
3.2 Methodology	86
3.2.1 Acknowledgment and use of extant literature	88
3.2.2 Co-construction of ‘meaning’ with the participants	93
3.3 Constructivist Grounded Theory (CGT) over other qualitative methodologies	99
3.4 Summary	103
Chapter 4: Methods.....	104
4.1 Introduction.....	104
4.2 Gaining perspective as an insider.....	105
4.3 Participants sampling, recruitment and study settings	107

4.3.1 Study settings.....	108
4.3.2 Theoretical sampling.....	112
4.4 Data collection	113
4.4.1 Ethical considerations	115
4.5 Summary	120
Chapter 5: Data Analysis	126
5.1 Introduction.....	126
5.2 Constant Comparative Method	129
5.3 Identifying categories	134
5.3.1 Being in a tug of war.....	136
a) Witnessing tension and marital breakdown between parents	137
b) Unequal distribution of parental attention	138
c) Unfair burden of domestic tasks.....	138
d) Being subjected to physical abuse.....	138
e) Being denied educational opportunities.....	139
5.3.2 Disadvantaging schooling (and social) systems	139
a) Being an object of curiosity	140
b) Being picked on.....	141
c) Struggling with school work due to visual impairment.....	141
d) Being excluded from learning.....	142
e) Dealing with rejection.....	143
5.3.3 Suffering double tragedy	143
a) Experiencing exclusion from employment	143
b) Double tragedy as it relates to romantic relationships	144
c) Being taken advantage of as a female with albinism.....	144
d) Inhibiting social wellbeing outcomes.....	144
5.3.4 Coping with ‘being different’	146
5.4 Linking categories	147
5.5 Identifying a central category	150
5.6 Theoretical sampling	153
5.7 The emerged substantive theory.....	160
5.8 Summary	162
Chapter 6: Presentation of Findings.....	163
6.1 Introduction.....	163
6.2 Being in a tug of war	166
6.2.1 Witnessing tension and marital breakdown between parents.....	167
6.2.2 Unequal distribution of parental attention.....	170
6.2.3 Unfair burden of domestic tasks	171
6.2.4 Being subjected to physical abuse	171
6.2.5 Being denied educational opportunities.....	172
6.3 Disadvantaging schooling (and social) system	173
6.3.1 Dealing with rejection	173
6.3.2 Being picked-on.....	175
6.3.3 Being an object of curiosity.....	176
6.3.4 Struggling with schoolwork due to visual impairment	179
6.3.5 Being excluded from learning	180
6.4 Suffering double tragedy	189
6.4.1 Experiencing exclusion from employment opportunities	190
6.4.2 Double tragedy as it relates to romantic relationships	198

6.4.3 Being taken advantage of as a female with albinism.....	203
6.4.4 Inhibiting social wellbeing outcomes	205
6.5 Coping with ‘being different’	209
6.5.1 Coping with negative learning experiences	209
6.5.2 Joining the Albino Foundation	211
6.5.3 Inuring self and retaliating to name-calling	213
6.5.4 Having faith and engaging in church activities	215
6.5.5 Relying on family for support	216
6.6 Consolidated reflection on findings	217
6.7 Summary	222
Chapter 7: Discussion of findings	224
7.1 Introduction.....	224
7.2 Being in a tug of war	227
7.3 Disadvantaging schooling (and social) systems.....	230
7.4 Suffering double tragedy	235
7.5 Coping and Resilience	240
7.6 Applying the Social Model of Disability to address ‘Being different’	242
7.7 Original contribution to knowledge	246
7.8 Trustworthiness of the study	249
7.9 Summary	251
Chapter 8: Reflexive account.....	252
8.1 Introduction.....	252
8.2 Reflexivity.....	252
8.3 Summary	264
Chapter 9: Conclusion	265
9.1 Introduction.....	265
9.2 Significant contributions to new knowledge.....	265
9.3 Implications for governance and social care policy on albinism and PWA in Nigeria.....	266
9.4 Limitations of the study	270
9.4.1 Sample size.....	270
9.4.2 Scope of the study	271
9.4.3 Age restriction for participating in the study.....	272
9.5 Recommendations	272
References.....	276
Appendix B: Approval from The Albino Foundation	304
Appendix C: Participant Information Sheet	305
Appendix D: Consent form.....	307
Appendix E: Interview schedule	308
Appendix F: Risk Assessment/Distress Protocol.....	309

List of Figures

Figure 1: Conceptual framework of the Biomedical Model of Disability (WHO, 1980, p. 10 - 11).	16
Figure 2: Equality vs. Equity (Interaction Institute for Social Change [IISC], 2016 Artist: Angus Maguire)	25
Figure 3: Conceptual framework for stigma (Link & Phelan, 2001).....	50
Figure 4: Screen image of line-by-line coding of data from a participant’s interview transcript	131
Figure 5: Memo written to document reflections on data	133
Figure 6: Illustrating the processes of disadvantaging life experiences for PWA.....	135
Figure 7: an illustration of the life-course experiences of participants that may be used as a conceptual framework to understand and explain what it means to be a PWA in Nigeria under the prevailing conditions.	149
Figure 8: Participants’ conceptualisation of “Being different”	152
Figure 9: Pattern to illustrate the teacher’s role in school experiences *CWA = Child with Albinism	156
Figure 10: Components of a disabling society	244

List of Tables

Table 1: Similarities between Constructivism Grounded Theory and Pragmatism.....	32
Table 2: Extracted deliverables from the National Policy on Albinism in Nigeria.....	79
Table 3: Participants' demographic information and list of interviews.....	122
Table 4: Conceptual meaning of social experiences.....	145
Table 5: Conceptual components of 'being different'	158
Table 6: Conceptual categories of 'being different' and its descriptive properties	165
Table 7: Recommendations	273

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Abstract

‘Being different’: realities of life experiences as constructed by persons with albinism in Nigeria – a PhD thesis by Adeolu Anthony Olagunju

In Nigeria, persons with albinism (PWA) continue to face a higher burden of health and social challenges in the society compared with the general population. PWA experience multi-faceted social injustices such as stigma, discrimination and exclusion from education, employment and social participation. These injustices are driven by the Nigerian society because of sociocultural perceptions and stereotypes associated with albinism which can be attributable to the lack of adequate understanding of the condition.

This research aimed to understand how the realities of being a PWA in Nigeria could be conceptualised based on their life experiences to develop a substantive theory of their social wellbeing status. By adopting constructivist grounded theory methodology, forty-two in-depth interviews were conducted amongst eleven PWA. Analysis identified three categories each of which embodies the multiple realities of disadvantages and exclusion experienced within the home, schooling, working and social environments at different stages of life. The concept of ‘*Being different*’ emerged from these categories to offer a theoretical explanation of what it means to be a PWA in Nigeria. The realities of ‘*being different*’ constitute processual social injustices for PWA because of how the Nigerian society is socio-culturally and institutionally configured to magnify the limitations of albinism above the rights and social liberties of the individual.

This research identified albinism as a disability and concluded that PWA are owed a moral and ethical obligation by the Nigerian society for them to be able to access the liberties and support necessary to secure their health and social wellbeing. The sustainable fulfilment of this moral and ethical obligation necessitates an inter-institutional collaboration and vigilance that should address the layers of injustices meted to PWA.

This study adds an original contribution to knowledge by offering a theoretical concept to qualify the social status of PWA in Nigeria, and thus, could be useful to inform appropriate health and social care interventions.

Overview and structure of the thesis

This doctoral research focuses on understanding and rendering an interpretive explanation of the social processes that constitute the realities of being a person with albinism in Nigeria. The ultimate aim of this study is to generate a theory that conceptualises the meanings and implications of these realities on the social wellbeing of persons with albinism (PWA) in Nigeria. The findings of this study offer a plausible theoretical argument that positions it within a social justice paradigm. Respectfully, I wish to declare I do not have albinism. In addition, the findings of this study do not make claims to a static truth about albinism and the life experiences of PWA in Nigeria. Having stated this, the theoretical explanations inherent in this study are an amalgam of my philosophical decisions and are only true if somebody else views them through the same lens of philosophical assumptions and decisions as I have. It must be noted that this research study does not promise to deliver change to the conditions of PWA in Nigeria but to develop a theory that may be used to inform positive social change.

This thesis is composed of nine chapters:

Chapter 1 provides a contextual and philosophical background for the study. The chapter explores the moral and philosophical influences that inspired the researcher's interest in the subject area.

Chapter 2 critically reviews the literature on the social aetiology linked with albinism. The literature review is framed around the generated emerged theory which highlights the historical emergence of social constructions for albinism and how movie industries around the world perpetuate misidentified images and perception of albinism and PWA. The chapter explores the implications of these social constructions on the life aspects of PWA within a broader sub-Saharan African context. Also, the chapter considers international and national

responses to the plight of PWA, and critically reviews the effectiveness of these responses.

The chapter draws to a close by making an argument for albinism as a disability which could be potentially managed within the framework of a social model of disability.

Chapter 3 details the methodological framework that directed the collection and analysis of data. It provides a critical comparison of qualitative research methodologies and provides justification for the adopted methodology. The chapter concludes that the methodological framework of constructivist grounded theory is most suitable and applicable for this study.

Chapter 4 explicates the methods and procedures that were employed to recruit and manage participants in compliance to acceptable ethical practice. The chapter goes further to delineate the strategies that were adopted to collect and make sense of data. The sum of this chapter exemplifies the trustworthiness of this study.

Chapter 5 outlines how data were analysed and interpreted. The analysis of data borrows from Strauss and Corbin's (1990, 1998) analytical procedures for grounded theory studies, and relies on the guidance of Charmaz (2006, 2014) for the inductive emergence of a substantive theory. In sum, the chapter highlights four conventional features of a typical grounded theory study which are: coding, the constant comparative mechanism, memo-writing, and theoretical sampling. The chapter ends with a presentation of the emerged substantive theory of 'being different'.

Chapter 6 presents the findings that were used to generate the substantive theory of 'being different', and ends with a descriptive reflection that summarises the findings.

Chapter 7 discusses the components of the emerged substantive theory of 'being different' within a theoretical framework that was influenced by Goffman's (1963) theory of stigma,

the theory of social justice as posited by Rawls (1971) and Powers and Faden (2006), as well as the theory of coping and resilience (Garmezy, Masten & Tellegen, 1984). In order to highlight the original contribution to knowledge of this study, the chapter draws on Charmaz's (2006, 2014) four criteria for assessing a grounded theory study.

Chapter 8 provides a critical reflexive account of the transference of influence between this study and the researcher. The chapter portrays the evolving positionality of the researcher during the developmental stages of the study.

Chapter 9 concludes this thesis by summarising the significant contributions of this study to knowledge. The limitations of these study were also identified. This chapter ends by stating the implications of this study for policy, and offers recommendations that may be useful for strategic health and social care interventions.

Chapter 1

1.1 Introduction

The Acheson Report (1988) defines public health as the science and art of preventing disease, prolonging life, and promoting health through organised efforts of the society. Fundamental to the practice of public health is the concept of improving health and wellbeing. While there is no single definition for wellbeing, the concept is generally accepted as the integration of physical, mental, emotional and social aspects of living through a holistic approach aimed to promote, improve and maximise overall health (Day, 2008; Dunn, 1973; Marks & Shah, 2004). It has been established that wellbeing cannot be achieved independently of societal structures such as family, relationships, community, accessible social goods and the policies that uphold the functionalities of social institutions (Thompson, Aked, Marks, & Cordon, 2008).

The principal proponent of the social justice theory John Rawls (1971) positions wellbeing as the direct derivative of a faultless administration of social justice. The central agenda of his ideology could be traced to the recognition of fundamental human rights, the plurality of individual choices, and a collective societal responsibility to provide accessible liberties to enable human rights and personal choices. A significant relevance of Rawls' ideology of justice to this study is that his underlying principles if judiciously applied, allow social wellbeing and security for even the most disadvantaged in the society.

Objecting to Rawls' position, Nussbaum (2006) presents a capability approach to the administration of social justice. She contends that Rawls' conceptualisation of who the most disadvantaged are in the society is measured only through a wealth and income index which does not necessarily acknowledge the complexities of securing wellbeing for people with disabilities (PWD). In other words, a disabled individual is likely to experience more

difficulty in overcoming barriers to wellbeing than someone who is considered poor in terms of wealth and income.

According to Nussbaum (2006), fulfilling a collective societal responsibility as Rawls (1971) proposes can only be feasible when everyone in the society is enabled and supported to exercise their liberties and choices according to their individual capabilities. A simple interpretation of this may be drawn from the following illustration: a blind child will not be able to access education as a fundamental human right if the educational system is not adjusted to provide learning aid for the visually disabled. However, a non-disabled child from a low-income family can access education by means of the free primary and secondary schooling systems provided by the State. Consequently, the educated child is more likely able to fulfil his/her social responsibilities, than the blind child who has not gained access to similar rights and liberties. Despite the identified disagreement on how to acceptably operationalise wellbeing among these proponents of the social justice theory, there is, however, uniformity in ideology. That is, for physical and social wellbeing to be achieved, there needs to be a mutually and beneficially reversible exchange of impact and influence between the individual and the society in which he/she finds himself/herself.

Social injustices continue to threaten the symbiosis that should exist between an individual and society and these consequently lead to inequalities in health and wellbeing. This is particularly critical to the wellbeing of people with disabilities (PWD). Disability like many other concepts in public health is a broad term which encapsulates an array of life-limiting conditions and impairments. The World Health Organization [WHO] (1980) defines disability as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (WHO, 1980, p.143). Similarly, The Equality Act 2010 enforced in the United Kingdom defines

disability as a physical or mental impairment that has a substantial and long-term adverse effect on an individual's ability to perform daily activities (Crown Copyright, 2010). Both definitions highlight the life-limiting characteristic of a disability. In any case, the WHO (2011) emphasises that disability is a derivative of an individual's personal condition(s) and socio-environmental factors.

Historically, the biomedical model of disability, also referred to as the Functional-Limitation Model has wielded a protracted influence on the understanding of disabilities. The Biomedical (Functional-Limitation) Model ascribes disability to the manifestation of disease (Parsons, 1951) and therefore focuses on pathology and cure of disease. This model holds that society has no impact or influence on an individual's health and wellbeing and as such, focuses on the impaired individual as one needing constant institutionalised care. Arguably, this presupposition, therefore, lends strength to the institutionalisation and segregation of disabled people such that they become categorised and objectified as sickly and undesirable. Indeed, this has been posited to be the bedrock of stigma, prejudice, and discrimination of PWD (Hahn, 1985).

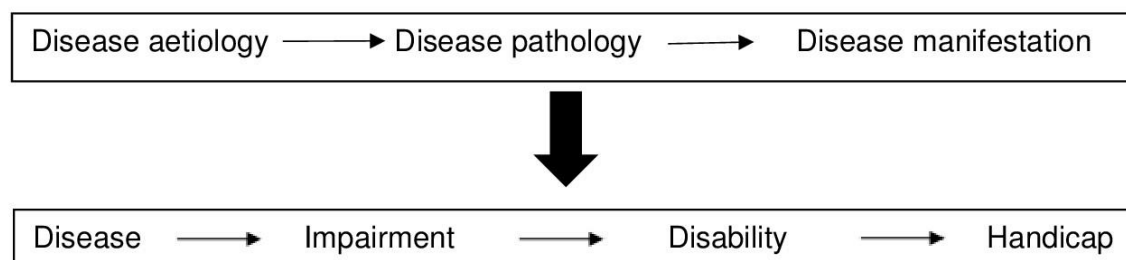


Figure 1: Conceptual framework of the Biomedical Model of Disability (WHO, 1980, p. 10 - 11).

The biomedical model of disability, however, fails to recognise that not all impairments that lead to disabilities are as a consequence of disease. In the first instance, impairment is defined as any loss or abnormality of psychological, physiological, structural functionality in any part

of the human body (WHO, 1980). Thus, impairment does not necessarily mean that the impaired individual is sick and needs a cure as implied by the biomedical model. Impairment may either be acquired or congenital. For example, acquired impairment could be the loss of a limb as a result of active duty in the army which can confine an individual to a wheelchair in the same manner as a spinal cord injury caused by a road traffic accident. In both cases, while the victim may have lost full or partial functionality of structural body parts for normal mobility, neither of the conditions was as a result of a disease and the individual should not be regarded as sick.

An example of congenital impairment which is of central importance to this study is albinism. Albinism is an inherited condition that reduces or disables pigmentation in the eyes, skin, and hair because of the absence of melanin. This condition is usually characterised by pale/white skin, sandy coloured hair and light brown eyes. Persons [or a person] with albinism (PWA) or ‘albinos’ as they are more informally referred to are naturally visually impaired and highly susceptible to skin cancer (King & Summers, 1988). At this juncture, it suffices to state that the most acceptable appellation in plural form is ‘*people/persons with albinism*’¹ while a ‘*person with albinism*’² will suffice in singular form. These phrases have been established to be most appropriate because they place the humanity of the person before the condition; whereas, ‘albino’ is perceived as derogatory. ‘Albino’ is therefore deemed an unacceptable term because it de-personalises the person, accentuates the condition rather than the person and adds to the stigma (Thuku, 2001).

¹ PWA is an acronym for people or persons with albinism

² A PWA is an acronym for a person with albinism

In western societies with predominantly Caucasian populations, PWA often pass unnoticed; in sub-Saharan Africa however, albinism is the most conspicuous of physical conditions which makes it difficult for PWA to blend in, and therefore predisposes them to unwanted attention due to physical appearance and skin-colour difference (Baker, Lund, Nyathi, & Taylor, 2010).

PWA gained attention for human rights protection against discrimination and bodily harm when continental and international media platforms were inundated with different reports on kidnapping, mutilations, rape, and murder of PWA from sub-Saharan Africa (Ntetema, 2008), particularly in Burundi, Malawi, South Africa, Tanzania and Zimbabwe. The violence meted out to PWA in Africa is speculated to be an off-shoot of various trado-cultural superstitions fuelled by societal perceptions of albinism which have consequently conferred a persona of magic and myth on PWA as supernatural beings (Alum, Gomez & Ruiz, 2009). In view of this, some men target females with albinism for sexual exploitation believing that such relationship will make them wealthy or lucky, and even cure them of diseases such as HIV/AIDS (Machoko, 2013). Regrettably, this has led to occurrences of rape of females with albinism (Duri & Makama, 2018). Similarly, some women with albinism who are married are often jilted after their husbands must have realised that there is no magic (Oduah, 2017). A more horrific occurrence is when PWA are abducted and slaughtered with the belief that their dismembered parts are potent materials in acquiring wealth, fortune and for curing diseases (Edevane, 2018; Manuel, 2018).

Admittedly, a plethora of scholarly work on the social aspects of albinism have emerged from eastern and southern Africa (Baker, Lund, Nyathi, & Taylor, 2010; Cruz-Inigo, Andres, Ladizinski & Sethi, 2011; Dave-Odogie, 2010; Tanner, 2010). Nevertheless, the originality of this study is attributable to being the first research attempt aimed at providing a conceptual

interpretation of the life experiences of PWA in Nigeria, which is used to develop a substantive theory on the meaning these experiences hold for their social wellbeing (see Section 7.6 for details).

Having already argued that the biomedical model of disability is inapplicable to PWA, the findings of this study and the generated substantive theory suggest that the social model of disability would be most appropriate and applicable to address the challenges of inequalities and social injustices PWA are likely to [continue to] face in Nigeria. The concept of a social model of disability as inspired by Professor Mike Oliver asserts that society is the conferrer of disability. He argues that physical impairment becomes a disability when society uses one's handicap as a criterion for isolation and exclusion from participating in social activities (Oliver 1996). He maintains that this manner of societal exclusion and marginalisation is an oppression to people with physical impairments (Oliver, 1996). Thus, society is tasked with the mandate of making reparations by removing all systemic barriers that restrict people with impairments from being progressive and participatory members of the society. The applicability of the social model of disability to PWA in Nigeria in light of the WHO's perspective on disability is articulated in Section 2.6.

Having hinted on the inclinations of my research interest, the subsequent sections of this chapter present the scope of this research project, and identify the personal connection I have with this study.

1.2 Moral philosophy

My interaction with experienced researchers has afforded me the knowledge to realise that in order for a doctoral pursuit to be truly meaningful, one's choice of research topic needs to

emanate from a passion for the subject area. I must acknowledge that my passion for this study is a product of my discovered purpose in life.

My upbringing influences my moral philosophy and subjectivities. I am from a Christian Catholic family and was baptised after Saint Anthony of Padua who lived his life in devotion and care for the sick and needy. My parents had wished that my life and inclinations would be inspired by the life and works of the saint after whom I was named. During my formative years and all through childhood, my parents and by extension the church community taught me the importance of living life according to God's will for humanity. The entirety of God's will and purpose for humanity according to the Christian faith is as recorded in the Bible³. During our family devotions, my parents encouraged my sister and me to take turns to read passages from the Bible and afterward, implored us to regard all people with love according to the will of God.

Even though I was too young to fully comprehend who God is at that stage of my life, I was sensitised to believe that God's love for humanity is so profound that he sacrificed his own son so that every human will enjoy life in the abundance of all that is good.

The fundamental principles of Christianity entreat us to love one another and treat the next person as we would love to be treated:

“Beloved, let us love one another, for love is from God, and whoever loves has been born of God and knows God” (1John4:7)

³ This thesis does not lay claims to God and Christianity as dogmatic notions of universal truth. The author acknowledges and respects the multiplicity of religions and practise of various faith or the lack thereof as a matter of individual preference

I was brought up to believe and accept that loving God is foremost demonstrated by loving all other people because we are all created equally in God's image and are all beautiful in His eyes regardless of race, social status and the presence of disease, deformity, or disability. Thus, the ideology of love and equality was the first component of my moral philosophy; and as a child, this was the perspective with which I viewed the world.

In congruence with the quoted biblical passage, several scholarly literatures on social justice appear to have identified the importance of love and care in ensuring and promoting equality (Lynch & Walsh, 2009; Lynch et al., 2016). The work of Kittay (2013) acknowledges that as humans, we are emotional beings with an innate ability to respond to love and care. This standpoint highlights the equality of love as an anchor for human interdependency (Kittay, 2013) and positions the concept of love and care in the centre of a collective social responsibility (Held, 1995; Nussbaum, 2003).

Similarly, Lynch (2013) and Lynch et al. (2016) have integrated the concept of affective equality as an advancement of Fraser's (2005; 2008; 2010) three-dimensional theory of social justice.

My continuous spiritual growth as a Christian brought me closer to discovering what I have been created to do as my understanding of the Bible deepened. During my university days as an undergraduate student, I began to make sense of my purpose in life and what I have come to believe God has called me to do. Guided by the Bible, I realised that though God had created people equally and intended love and equality to be the moral principle for human co-existence, God recognises that the social transactions and positions of men have created inequalities. In light of this, God acknowledges the power imbalance amongst humankind as recorded in Matthew 26:11 "*You will always have the poor among you...*", and implores us to

promote fairness and equality by correcting injustices and alleviating the plight of the socially disadvantaged:

“...learn to do good; seek justice, correct oppression. Protect the rights of the poor. Help those who are oppressed” (Isaiah 1:17; Psalm 82:3)

However, if men continue to fail to treat one another with love, fairness, and equality, the Bible foretells a futuristic time when God himself will administer judgement according to his will and purpose for humanity: *“...for he is coming to judge the earth. He will judge the world with justice and the peoples with fairness”* (Psalm 98:9). Even Jesus Christ, whom I believe to be God’s physical manifestation, was recorded in the Bible as having fulfilled his earthly ministry in accordance with the principle of love and fairness. If nothing else, the Bible is clear about defining God as an advocate of love and justice.

Following the completion of my undergraduate studies, I realised that God’s will for me revolves around advancing social justice and fairness, in like manner as the earthly ministry of Jesus Christ and my patron saint. It occurred to me that my purpose in life is to use my opportunities and advantages to address issues of inequity, inequality and social injustices with whatever resources I have been blessed with.

While I might have grown to understand and extend empathy through my practice of faith, I had the opportunity to nurture my passion for equality and social justice as a Master’s degree student of Public Health. I was tutored by a philosopher whose passion to combat inequalities of health, and social injustices could not be over-emphasised. At the end of my eighteen-month postgraduate study, the works of Mabhala (2013; 2014; 2015a; 2015b; 2015c) had inspired my interest to understudy social inequalities and injustices as relating to vulnerable and marginalised people.

This set me on the path to investigate PWA, who are a hidden and seemingly negligible social group in my home country Nigeria, where they are vulnerable to multiple layers of social injustices and health risks. This research journey has enabled me to attain a moral and intellectual position, which is that disability support should be provided to PWA as a life-long intervention considering that they have to endure life-limiting disabilities due to visual and dermal impairment (see Table 7). The provision of disability support across all social institutions would improve their chances at pursuing life opportunities, and more importantly, enable them to have equal access to social goods and other determinants of health and social wellbeing (Marmot & Wilkinson, 2005). My argument here is that accessible health and social care services should be made readily available to those needing them most in order to bridge the gaps in health and social security between the most and least advantaged.

Before I delve too deeply, it is imperative to state that my core interest is in addressing the health and social inequities that are characteristic with having albinism as a means of achieving health and social equalities for PWA. Firstly, I will attempt to define health inequalities because it is a more popular concept than health inequities. The concept of ‘Health Inequalities’ has occupied the centre stage of public health discourse since the Black Report (Black, Morris, Smith & Townsend, 1980). Health inequalities are measurable systematic differences in the health of people occupying unequal positions in society occurring as a result of variations in income, social class, ethnicity and geography (Graham, 2009).

Health inequalities have endured through time, and they occur in every country (Mackenbach et al., 2008). For instance, life expectancy in Haiti is 64 years, whereas people in Japan could expect to live up to 84 years (World Bank, 2019). On the one hand, a plausible reason for this variation can be attributed to the application of advanced science and technology in Japan

which is aimed at improving health and social conditions, thus prolonging life (Oeppen, 2019); while on the other hand, the recurrence of natural disasters in Haiti continues to destabilise both national economy and productivity (Zuraik, Sampalis & Brierre, 2018).

In contrast to health inequalities, health inequities are preventable and unnecessary differences in health often attributable to unjust health and social policies, thereby effecting an unfair distribution of health risks and social resources (Marmot et al., 2012; Whitehead, 1991). Providing clarity to the concept of health equity, the WHO (2019) through its online information page on health topics states that “ideally everyone should have a fair opportunity to attain their full health potential and that no one should be disadvantaged from achieving this potential”. Although I acknowledge that the strategies to tackle health inequalities advocate for equal access to health and social resources (Dahlgreen & Whitehead, 2006; Morrison et.al., 2014), the reality of life is that not everyone will have the same capacity to enable equal access to social goods. As a result of ancestry and inheritance, some people will always be more socially advantaged than others.

In the context of this study and as suggested in the recommendations in Section 9.5, health equity is all about instituting fair social policies to enable equal access to resources that will level the playing field for those who are naturally and socially disadvantaged [such as PWA] without disfavours other members of the society. My point of view here is that if the society is fairly configured, then everyone will have equal access to the social goods that ensure and sustain sound health and social wellbeing. This is to say that equity and social justice is the bedrock of health equality.

For the larger audience outside academia who may have access to this thesis, my point of view on equality and equity is appositely illustrated by the figure below.

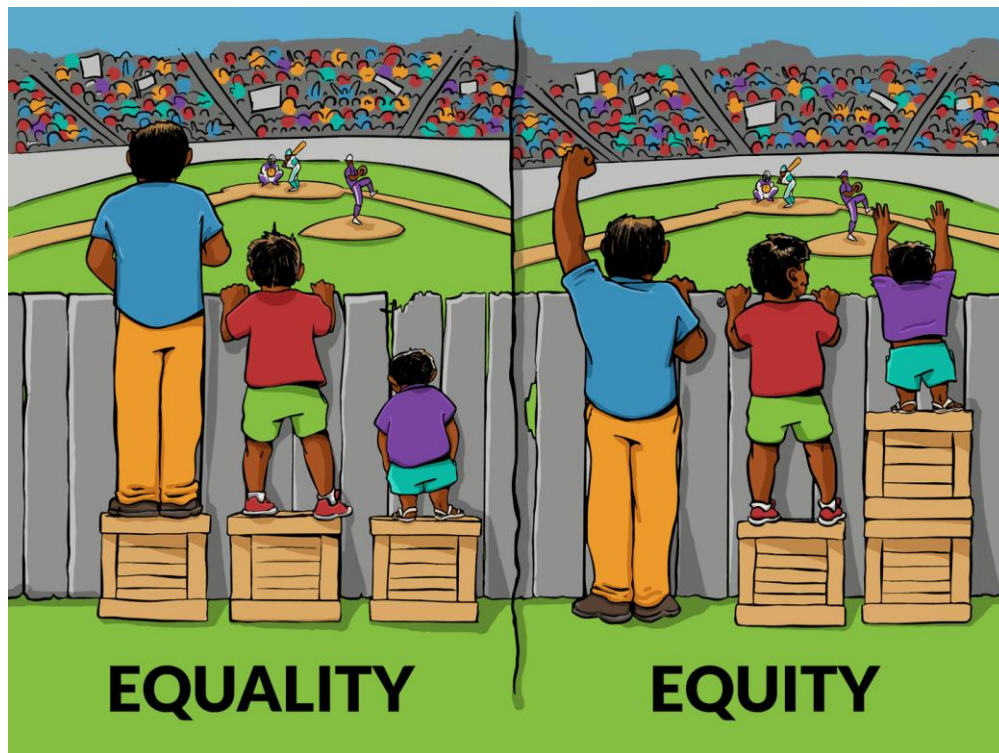


Figure 2: *Equality vs. Equity* (Interaction Institute for Social Change [IISC], 2016 / Artist: Angus Maguire)

Figure 2 above illustrates three individuals who have different capabilities but desire to watch the same game. Thus, the opportunity to watch the ongoing game is the ultimate goal of each of them.

To put this illustration in context with this study, I consider this ‘ultimate goal’ to mean the same thing as the collective social goods [such as education and social security] that are essential to secure health and social wellbeing. The first half of the figure illustrates ‘Equality’ based on the assumption that each of the three individuals should be provided with the same support which in effect did not enable equal opportunity to watch the game. However, the second half of the figure exemplifies ‘Equity’ which demonstrates fairness by providing supported access based on each individual’s capabilities such that they are all able to watch the game, and thus, achieve the aim of enabling equal access to the same opportunity.

1.3 Research philosophy

An integral step in the sequence of philosophical decisions that were made to direct this study is delineating my philosophical assumptions about knowledge, and about how knowledge should be acquired. According to Creswell (2007), identifying the assumptions and worldview that are consistent with one's research questions is the first task when designing a research study. Similarly, de Vaus (2001) states that "the function of a research design is to ensure that the evidence obtained enables us to answer the question as unambiguously as possible" (p.9). A well-articulated research design clarifies the importance of aligning the pertinent philosophical perspectives with the stated research aim and objectives. Consequently, I adopt Crotty's (1998) framework of four questions as an approach to clarifying my research philosophy.

The first question addresses the nature of reality, otherwise referred to as ontology. The ontological stance of this study draws on a collection of scholarly evidence which has established that social inequities and inequalities are enabled by social injustices and are a continuous threat to population health and wellbeing (Chapman & West-Burnham, 2010; Dorling, 2015; Peter, 2001). As I hope that the reader will identify later on in the 'Presentation of Findings' chapter in this thesis, this ontological knowledge may be considered a plausible representation of the realities of life experiences for PWA in Nigeria. Consequently, the adopted ontology can be situated within the elements of two extant theories, namely: (1) the structural theory of health inequalities and (2) Rawls' political conception of justice and reasonable citizenship.

Firstly, I consider the Structuralist or Materialist theory of health inequalities as postulated by the Black Report (Black, Morris, Smith & Townsend, 1980) which posits that the physical and social aspects of the environment are the key determinants of health outcomes. Physical

aspects of the environment such as disabled access to buildings can determine ease of access for disabled people into venues for employment opportunities, schooling, marketplaces, recreational grounds, and healthcare service delivery. Similarly, the availability of social drivers such as the provision of adequate housing, quality, and inclusive education, as well as even distribution of income can reduce the impact of health inequities on health and wellbeing. For example, between 1999-2010, the fatal accidental drowning rate among African American children of ages 5-8 was 10 times higher than among Caucasian American children of same age (Gilchrist & Parker, 2014). It was observed that this was caused by the absence of barriers in public swimming pools constructed in ‘black neighbourhoods’ which contributed to racial differences in the United States. Gilchrist and Parker (2014) argue that the impact of this type of structural inequality is evident in the incidence of brain damage and the development of learning disabilities among African American children as a result of drowning injuries.

Similarly, the importance of necessary social drivers is emphasised in the unavailability of Braille for the blind in Nigerian schools which have been reported to be the most significant determinant of street begging, especially in northern Nigeria (Ademola-Popoola, Tunde-Ayinmode & Akande, 2010; Dineen et al., 2008). Blind people are unable to obtain optimal education as children, which subjects them to a life of poverty in adulthood, thereby widening the margin for social inequities and inequalities. Following this perspective, it is reasonable to argue that the availability of learning materials for the visually impaired or the lack thereof has the potential to determine learning experiences for PWA in the school environment. Therefore, the logic behind the structuralist or materialist theory of health inequalities makes sense to me; and with this, I have been able to accept that diminished structural inequalities

will invariably bring about a considerable reduction in the manifestations of health and social inequalities.

Secondly, Rawls' (1971; 1999) political conception of justice and reasonable citizenship as embedded in his theory of justice has similarly influenced my intellectual worldview. He propounds that freedom and equality are mutually inclusive components of a society. Rawls defines 'justice' as 'fairness'. He postulates that a society is an institution which should be designed to advance the good of all while at the same time is being effectively and continuously regulated by a public conception of justice. In essence, Rawls envisages a society in which (i) everyone accepts and knows that the others accept the same principles of justice, and (ii) the basic social institutions irrevocably satisfy these principles. He argued that every individual reserves the prerogative to enjoy legitimacy and equal access to social goods both of which must be impervious to political bargaining and societal infringement.

In an attempt to clarify his perspective, Rawls (1999) likened justice as fairness to a contractual agreement between the society and all acceptable principles of justice. Thus, justice must always complement fairness by placing a priority on what is good over what is right (p. 28).

He further stated that justice as a communal policy must be implemented such that liberty, opportunities, income, wealth, and all the determinants of self-respect are fairly distributed. Fairness in a complementary capacity is to be delivered through a concept of reasonable citizenship which he conceptualised as the "criterion of reciprocity" by stating that:

"citizens are reasonable when viewing one another as free and equal in a system of cooperation over generations, and they are prepared to offer one another fair terms of social cooperation . . . and they agree to act on those terms, even at the

cost of their own interests in particular situations, provided that others also accept those terms. For those terms to be fair terms, citizens offering them must reasonably think that those citizens to whom they are offered might also reasonably accept them. They must be able to do this as free and equal, and not as dominated or manipulated, or under the pressure of a superior political or social position" (Rawls, 1996, p.49 – 54).

Considering the works of Rawls (1971; 1999) alongside the Black Report (Black, Morris, Smith & Townsend, 1980), and Wilkinson and Marmot (2003), it might be argued that the knowledge relating to social inequities and injustices are subjective to the configuration of a society based on how the different social institutions interact with one another. The notion of social inequities as a subjective derivative of the socio-economic/socio-political configuration in any given population is further evidenced by more recent empirical studies (Kelley & Evans, 2017; Kuhn, 2019). Similarly, this notion resonates with the findings in this study. At this juncture, I wish to declare that at the time of completing this thesis, the findings in this study are both subjective and relative to participants' perceptions of how the Nigerian society treats PWA.

Drawing once again on Crotty (1998), the second question in the framework for designing a research study requires clarifying the epistemology, that is, the study of knowledge which in simple terms refers to 'how do we know what we know'? An epistemology cannot be deconstructed in isolation from the theoretical perspectives that underpin its application (Creswell, 2007). Bearing in mind that the quest to answer the research questions determines the research design, the philosophical assumptions that are relevant in answering my research questions are those that are consistent with Charmaz (2006, 2014). Subsequently, Charmaz was used to address the third and fourth questions in Crotty's framework with respect to

adopting an appropriate methodological approach and corresponding methods of data collection and analysis respectively.

1.3.1 Aligning with Charmaz's Constructivist Grounded Theory

The paradigmatic sense I made out of my ontological assumption about social inequities, social injustices and implications for wellbeing as being subjective to societal configuration firstly recognises that the meaning and manifestation of reality differs from person to person – this aligns with Schutz's (1945) articulation of multiple realities. Secondly, I believe that these realities occur within the context of a given social environment which is shaped by the influence of historical and socio-cultural beliefs that have become evident in everyday interactions in that given environment – this keeps with the perspective of symbolic interactionism (Blumer, 1969).

Thirdly, I believe that realities are not static but are able to evolve as the social environment and its emergent social interactions change with time. This conforms to Charmaz's relativist worldview of realities as ongoing manifestations of historical, social and situational implications (Charmaz, 2017). Fourthly, I believe that an endeavour to gain knowledge of, interpret and construct the meanings of these realities should not be attempted without the active participation of the individuals who have the first-hand knowledge of experiencing these realities. This rests on Charmaz's (2000, 2006, 2014) constructivist epistemology of co-construction of interpretive meaning with participants.

The core of my research philosophy aligns with pragmatism and by extension, constructivist grounded theory (CGT). Pragmatism assumes that proffering meaning and solutions are driven by practical applications of knowledge, and thus, positions it as a philosophical tradition with an undeniable commitment to social justice (Charmaz, 2014; 2017). In other

words, answering my research questions requires a pragmatic approach to data collection and analysis. While pragmatism offers one way to influence social reform, CGT offers analytic methods to delineate and make visible the processes and actions that underlie various manifestations of injustices that are pertinent to trigger correctional social reform. Arguably, this standpoint suggests the reason Charmaz (2010) advocates CGT as suitable for social justice inquiry and thus, a good fit for this study.

Pragmatism and CGT view reality as fluid, socially constructed, multifaceted and constantly subjective to change. Both philosophical perspectives view reality as a practical product of human agents. When presented with the processes and action that constitute these realities, people's sense of self is enabled to morph so as to birth new meanings of reality.

In this sense, 'meaning' is an ongoing process derived from practical social interactions (Blumer, 1969) in very much the same way that 'self' and reality is also a process (Gecas, 1982). What this means for this study is that 'being different' as a theoretical concept of life experiences for PWA in Nigeria (see Sections 5.5-5.7) is a process that is adaptable to change positively in line with egalitarian ideals if society's interactional actions are re-engineered accordingly (Charmaz, 2014). The table below illustrates the similarities of assumptions between pragmatism and CGT.

Table 1: Similarities between Constructivism Grounded Theory and Pragmatism.

Pragmatism	Constructivist Grounded Theory
Views reality as social	Views reality as social
Locates experience in its social context	Locates experience in its social context
Assumes processes	Studies processes
Presupposes a fluid, somewhat indeterminate reality	Presupposes a fluid, somewhat indeterminate reality
Views human beings as agentic actors	Views human beings as agentic actors
Acknowledges multiple perspectives	Seeks multiple perspectives
Emphasizes the significance of language	Pays analytic attention to language
Studies people's actions to solve emergent problems	Studies people's actions to solve emergent problems
Provides the roots of a theory of action	Provides methods for theorizing action
Sees meanings and actions as emergent and as affecting each other	Studies emergent meanings and actions and how each affects the other
Unites the viewer with the viewed	Bonds the researcher with the researched
Treats truth as conditional	Views truth as conditional
Advocates social reform	Provides a method for social justice inquiry

Source: Adapted from Charmaz (2008, p.136)

One important similarity between Pragmatism and CGT is the theoretical perspective of symbolic interactionism, that is, the recognition of people and their use of language as transactional tools for constructing and interpreting realities.

The assumptions in line with symbolic interactionism theorises that we are born and enculturated into a society in which culture, language, traditions and every other constituent of transactional communications already have symbolic meanings – meanings that we are

expected to learn and adopt even as we begin to practically define our own sense of self and identity (Charmaz, 1995; 2002). This underscores the relevance of symbolic interactionism as a theoretical perspective that merges Pragmatism and CGT, and thus, facilitates the potential to establish a relationship of mutual respect and acknowledgement of subjectivities between researcher and participants.

Re-echoing the views of Mead (1934), Charmaz (2014) positions the use of communal language and associated dialectical meanings as consequential to the ideology of self. Her point of view on symbolic interactionism posits that what society makes of us wields an influence over how we define ourselves even if we do not accept it. For instance, as in the case of the findings in this study, all participants referred to themselves as ‘albinos’ even though it is presently considered a pejorative nomenclature for human identification. However, this does not mean that they accept the socio-cultural identity of PWA as supernatural beings. Furthermore, albinism, within a Nigerian and even in a broader African context remains a symbolic condition for both the society and PWA because of the historical and socio-cultural stereotypes with which albinism is being constructed (see Section 2.3).

Kathy Charmaz’s (2006, 2014) CGT assumes that reality is continuously constructed by people through their actions and acknowledges the researcher’s role in interpreting studied reality. Based on this premise, CGT recognises that peoples’ actions and even the researcher’s roles are not without historical, social, and situational ramifications. In this view, Charmaz favours a relativist ontology that acknowledges that a social reality can be experienced in multiple ways. For example, the social reality of being disabled can be experienced in a variety of ways with respect to the kind of disability that is being considered. Hence, an amputee may not have similar social experiences as someone with learning disabilities. Charmaz (2006, 2014) maintains that the realities of social experiences

are both processual and multifaceted, and are continuously constructed under specific conditions in a given context. Thus, the interpretations given to social experiences are relative to the conditions and context within which they occur and are consequently subjective to change if the underlying conditions and contexts do change.

Springboarding from these points of view, Charmaz (2011) offers CGT as a useful method for a social justice research study because it (i) acknowledges, respects and considers participants' voice and their relative standpoints (ii) recognises and declares the researcher's subjectivities (iii) allows the researcher to locate his/her subjectivities by engaging in reflexivity, (iv) adopts sensitizing concepts such as power, privilege, equity, and oppression through which reality can be interpreted (v) allows researcher to remain attentive [and be able] to identify variations in the meaning of reality for participants.

Considering these rationalisations, Charmaz (2007, 2011) contends that adopting CGT strategies can help researchers to understand the socio-structural and situational contexts that enable the conceptual processes of inequities and injustices. More importantly, CGT methods have the potential to aid a researcher to identify the links between the individual and communal realities of suffering, disempowerment and how these constitute multiple realities. She argues that all these can sharpen the analytical reach of a researcher to generate a theory that has the potential to make the work visible, give voice to participants and engender positive change in social policy and practice.

These assumptions convince me that answering that the questions this study intends to answer requires a pragmatic approach within the methodological framework of CGT. Thus, it is with these philosophical underpinnings that I have been able to construct the abstract knowledge to interpretively explain what it means to be a person with albinism in Nigeria.

1.4 Research aim and objectives

The philosophical underpinnings that helped me to conceptualise the research scope are presented in sections 1.3 and 1.4 of this chapter.

Aim: To use the life stories of PWA in Nigeria to construct a theory about their social wellbeing.

Specific objectives include:

- i. To explore the experiences of being a PWA in Nigeria
- ii. To generate a theory on what it means to be a PWA in Nigeria

The research questions addressed are as follows:

- i. What does it mean to be a PWA in Nigeria?
- ii. How does being a PWA in Nigeria impact social wellbeing outcomes?

1.5 Summary

In this chapter, I have attempted to situate the condition of albinism within the context of a disability that has socio-structural implications for social equity and social protection. I have made an argument for the importance of addressing the social inequities that create disadvantages for people with disabilities so that the margins of inequalities can be practically narrowed. In addition, I have provided a reflection of the faith-based influence that inspired my moral perception of love, solidarity and justice as fundamental principles to fostering human relationships in the society. Similarly, I have drawn on a collection of research philosophy that underlie my intellectual subjectivities of what knowledge is and how to acquire it, thereby, providing a sense of direction to where this study is headed.

Chapter 2: Literature review

2.1 Introduction

This chapter pivots from the historical origins of identification of albinism and PWA; onto the role of symbolic interactionism and how it permeates the entertainment industries across the world to propagate the social constructions of albinism and PWA. Also, it critically explores different themes drawn from the scholarly and journalistic literature on albinism across varied population settings, with a particular focus on the myths and superstitions that have been used to construct albinism and PWA socially. Furthermore, it goes on to argue albinism as a disability, critically appraises international response to the plight of PWA and narrows it down to the Nigerian context of addressing social inequities for PWA, examining strengths, extent, and limitations. The chapter ends with an argument that appeals for a repositioning of the legislation prohibiting discrimination against people with disability in Nigeria in order to provide adequate social security for PWA.

There are several contentions on how and when to approach the literature review in studies that have adopted a grounded theory methodological framework. Classic grounded theory adopts an objective stance and distance from established evidence until after conducting the data analysis (Glaser & Strauss, 1967; Glaser, 1978; Glaser, 2012). Understandably, this is to curtail the possibility of attending to data with preconceptions that may potentially adulterate the rigour and credibility of the study (Holton & Walsh, 2016). Nevertheless, scholars who identify with constructivist grounded theory (CGT) support a preliminary glance at prior studies, not as a point of import to data analysis, but to get familiarised with how the topic area has been studied in the past (Charmaz, 2005; Henwood & Pidgeon, 2003; Kelle, 2014). This approach aims to offer the researcher some insights into the concepts that he/she may potentially come across or take for granted as the case may be, so as to avoid repeating or

replicating research and be alerted to gaps in evidence for subsequent comparative critique as the study develops (Thornberg, 2012). Ultimately, Charmaz (2006, 2014) recommends that literature review should not drive data collection and analysis; instead, the literature review should be written through the lens of the emerged grounded theory. My understanding of this point of view is that while it is permissible to be aware of and acknowledge prior studies relating to a study, the literature review should be both focused and derived from the findings that have emerged from data analysis – this in itself gives credence to the abductive nature of the study. Thus, the sections in this chapter have been written to provide a sense of context that merges evidence from extant literature with the developed substantive theory of ‘Being Different’ [see Section 5.7], as it brings into view various pieces of evidence that underscore the social injustices and other featured realities that are characteristic of people with albinism (PWA). The contentions around the timing and positionality of a literature review in grounded theory are discussed in details in Section 3.2.1.

2.2 Albinism: definition and manifestations

The National Organization for Albinism and Hypopigmentation [NOAH] (2015) defines albinism as a congenital condition characterised by little or no pigmentation in the eyes, skin, and hair due to the absence of melanin. There is a consensus that the embryonic cause of albinism is attributable to the inhibited synthesis of melanin from the amino acid tyrosine by mutated genes (Dolinska et al. 2017; Olivares & Solano, 2009).

The exact global prevalence of people with albinism (PWA) is not known. However, various studies have attempted to present certain estimates. Wiete (2012) reported a 1:20,000 ratio for albinism prevalence in Europe; 1:17,000 in the United States (Wan, 2003) and 1:5000 in sub-Saharan Africa making this the region with the highest incidence. Continental estimates by Thuku (2011) and Ikuomola (2015a) was that Tanzania had about 170,000 PWA (1:290) and

South Africa records about 13, 584 PWA (1:3900) respectively. The prevalence of albinism in Nigeria is estimated at 1:30, suggesting a PWA population of about 6,000,000 people which may be the highest in the world (Aduge-Ani, 2014).

Physical and physiological manifestations of albinism as immediately observed in the eyes, skin and hair colour are determined by the type of albinism an individual is diagnosed with. According to Witkop (1989), oculocutaneous albinism (OCA) which is the most common type of albinism impairs the eyes and skin and is classed into four (4) variations, each with its own prevalent population: OCA type 1 individuals tend to have milky skin, white hair and blue eyes, usually expressed amongst Caucasians. However, with age progression, the skin and hair may begin to darken. OCA type 2 is the most severe form of albinism and widely predominant within sub-Saharan African, African-American and Native American populations. OCA type 2 is characterised by pale yellowish-brown hair and skin colour, and dilated iris (Summers & Hand, 2019). Due to the abnormal presentation and movement of the eyes, OCA type 2 can be diagnosed within the first three months of life (Lewis, 2012).

Individuals with OCA type 3 have characteristic pale skin, sandy-coloured hair and translucent eyes that fall within the legal definition for blindness. OCA type 3 is the mildest variant in terms of visual impairment. It presents mostly in black South Africans and manifests as reddish-brown colour in the skin, hair and eyes (Manga, Kromberg, Box, Sturm, Jenkins & Ramsay, 1997). OCA type 4 is most expressed in East Asian populations. It shares similar symptoms with OCA type 2. However, vision is reported to improve after early childhood because the skin cells in individuals with OCA type 4 are able to synthesise pigmentation within near-normal range (Hayashi & Suzuki, 2017; Inagaki et al., 2005).

Other types of albinism transcend expected physical presentations into more systemic symptoms. The works of Han et al. (2015) identified X-linked ocular albinism as endemic to

males; vision problems are present, but eye, skin and hair colour is nearly normally pigmented. Hermansky-Pudlak syndrome is an unusual type of albinism with high susceptibility to bleeding disorders such as haemophilia, bowel, heart, kidney and lung diseases (Oiso & Kawada, 2013; Wei, 2006). Chediak-Higashi albinism, another rare variant presents with silvery hair, gray skin and defective white blood cells that render the individual to be immunocompromised (Montoliu et al. 2014).

It is reasonable to posit that regardless of the type of albinism an individual is diagnosed with, eyes and skin impairment remains constant. The implication of which is that persons with albinism (PWA) will invariably appear and behave differently in any given population.

Having stated these, I wish to reiterate that the scope of this study is particular to Nigeria. All the study participants have oculocutaneous albinism type 2. Thus, the absence of melanin in their body implies that ultraviolet radiation from the tropical sunshine is readily absorbed into their skin and eyes. This predisposes PWA in Nigeria to skin cancer, natural visual impairment and other aberrant eye behaviours such as strabismus (crossed eyes) and nystagmus (involuntary, rapid and repetitive movement of the eyes) (Fuller & Hay, 2014). Given the severity of visual impairment, most PWA are considered legally blind and therefore disabled because their eyes are not able to focus and accommodate vision (Brilliant, 2015; Estrada-Hernández & Harper, 2007).

2.3 Origins of social identity for Persons with Albinism

2.3.1 A descriptive historical perspective

As a way to fully comprehend and appreciate what it means to be a PWA, it is crucial to uncover the origins of racial categorisation based on skin colour, which has played a major role in the social identification of PWA. As permitted by available literature, this section traced the conceptualisation of different social identities for PWA as chronicled during the era of expeditions and slave trade to the African continent.

First-century primogenitors of geography and philosophy such as Pomponius Mela and Ptolemy acknowledged the existence of white-faced, nocturnal people [supposedly PWA] whom they called *Leucoaethiopes* as dwellers on the African mainland (Little, 1995). In his treatise, Little (1995) traced the first record of a PWA in Europe to 1519 when Spanish explorer Hernan Cortes visited Moctezuma II. Little's (1995) exposition of Cortes' travelogue revealed witnessing people with white faces, white bodies and white eyelashes working in the monarch's court. As this was only mentioned in passing, a convenient conjecture would be that these seemingly white-skinned creatures were not important enough to draw academic inquisitiveness given their lowly state in the palace. Furthermore, this also suggests that they might have been slaves transported to Spain from Africa.

Human differentiation into racial categories began to take shape as a nascent abstractness in the sixteenth century, even though the word 'race' did not appear in literature until 1694 when the first edition of French dictionary *Dictionnaire de l'Académie Française* defined 'race' as '*lignée*', that is, 'lineage of families or beasts' (Hudson, 1996).

The theorists and philosophers of the Enlightenment Era in the eighteenth century sought to formally conceptualise the varied racial distinctions amongst man beyond mere geographic

localities. Fundamentally, European explorers presumed themselves superior to Africans and other non-European populations. Whilst this assumption of superiority was largely based on the crude and rustic civilisation of the African and native peoples [as against the urban sophistication of the Europeans], the visible skin-colour differentiations also bolstered the need for racial categorisation. Thus, for all intents and purpose, whoever was not a ‘white man’ was classified as a beast, and everything else in between was considered a monstrosity (Africanus, 1896; 2010). This classification was evident in Ogilby’s (1670) travelogue in which he implied that some nations like the Kabangos in West Africa and the Hottentots in southern Africa were beastly in nature and behaviour. In addition to the emerging sub-humanification of the ‘black man’, certain influential authors at that time declared that the black African man was biologically inferior to the whites and therefore should be subjugated (Cox, 1959; Lovejoy, 1986; Raynal, 1770). This may have been the precursory reasoning that instigated slavery and colonialism. At this juncture, one may begin to question the relevance of albinism to racial categorisation. The valid argument that attempts to answer this is that the African was appended a beastly identity and consequently deemed undeserving based on skin-colour. Thus, the black man’s humanity was subjected to discrimination, imperial hegemony and ultimately, stigmatisation. This concept formed the basis for the social misidentification of the PWA, whose unfathomable skin colour and appearance place them below the “beastly black African” (Griffin, 1999. p.14).

Scholarly interest in albinism and PWA gained strength in the seventeenth century when English sojourner Andrew Battel (1614) was received by the King of Loanga in the Central African Republic of Congo who had *dondos* [persons with albinism] living with him. Battel described the *dondos* as having red eyes that never stopped moving in their heads, and red or yellow hair and skin as pale as the skin of a corpse. Battel added that even though they

looked like Europeans, they squinted during the day whilst their vision came alive at night. Battel's narration of his encounter with the PWA in the king's court did more to accentuate their seemingly unnatural appearance rather than to appreciate their uniqueness. About seven decades after Battel's travel journal was published, Olfert Dapper (1686), a Dutch physician and historian conducted an ethnographic synthesis on a compendium of travelogues and concluded that the PWA or *nègre blanc* [white negro as the French called them] was indeed a monster, undesirable and unworthy of inclusion in the human society. Dapper added that the early black African natives were always at constant war with the PWA, so much so that PWA were not allowed societal livelihood, and were always hunted down like animals; if caught, the men were emasculated and enslaved to serve as court eunuchs, whilst the women were exiled all in an effort to prevent procreation of future PWA. Such was the lowly, undesirable state of the PWA that even indigenous black Africans found them distasteful and monstrous. Dapper's insinuations echoed a wide-spread paradigm that the PWA was exclusive to Africa.

Academic interests in PWA were once again kindled when Claude Helvetius (1734) presented his findings to the Academié Royale des Sciences [French Academy of Sciences] in Paris. Helvetius had sought his colleagues' intellectual contributions having just returned from Surinam where he had been consulted to examine a *nègre blanc* baby boy born to two black African slaves who had been pronounced an imbecile and unintelligent. Helvetius' examination notes recorded that the boy with albinism had woolly hair and a flat nose, both of which were distinguishing phenotypes of an African which conclusively implied that the boy was not Caucasian. The Academy was confounded to fathom how a white-skinned child could have originated from two black parents. Even though this posed a biological conundrum, this learned society did not append a monstrous identity to the PWA but rather sought to unravel the genetic mystery behind the PWA's racial uniqueness. An afterthought

that springs to my mind at this juncture is that the unseemly unintelligence of the boy with albinism may have been an offshoot of the pregnancy stress his mother endured on the long, arduous voyage on the slave ship from the African continent.

In 1744, French naturalists had the opportunity to examine a PWA first-hand when a four-year-old boy with albinism born in South America was exhibited for scientific curiosity at the Academié Royale des Sciences. The reflections of Pierre Louis Moreau de Maupertuis' examination of the boy as documented in his *Dissertation physique à l'occasion du nègre blanc* [Physical dissertation of the white negro] (1744) and *Vénus physique* [The Earthly Venus] (1745) became fundamental in changing Europe's understanding of albinism. Maupertuis' epigenetic theory firstly sought to refute Linnaeus' (Linnaeus, Engel-Ledeboer & Engel, 1735) philosophy of preformationism which proclaimed that the PWA's foetus originated from a preformed life form in the egg, thereby making the delivery outcome monstrous and undesirable. In his argument, Maupertuis speculated that a PWA was born just as naturally as normal-pigmented human through fertilization from the union of two seminal fluids. Maupertuis further posited that the black race must have originated from white genes and that nature had the ultimate prerogative to produce new and strange things; as a result of which sometimes, genetics accidentally revert back to the white variety whenever a PWA was born - this philosophy was later known as Maupertuis' theory of accidentalism.

As far as Maupertuis was concerned, he had discovered the link between the white and black race and assuredly, their shared human origins. This paradigm gave the PWA a more humanistic identity than ever before. In all its brilliance, however, Maupertuis' humanification of the PWA whilst laudable failed to answer questions such as: what is the aetiology of albinism? How do causative genetic accidents occur? If the results are unpredictable and undesirable, are they preventable?

Plausible answers to these questions were proffered by naturalist Comte de Buffon (1749), a colleague of Maupertuis' who had also witnessed the exhibition of the boy with albinism at the Royal Academy of Science. Whilst he agreed with Maupertuis' theory of epigenesis and accidentalism, Buffon still wondered if the outcome of a genetic accident should not be considered a monster. In the developmental stage of his publication, Buffon (1749) argued that the black man originated from the white race. He attributed the presence and absence of black pigmentation as well as other tones of the human skin colour to the effects of different climates. He opined that the black man's skin colour was due to continuous exposure to the tropical climate that is peculiar to the African continent. In line with this reasoning, Buffon was certain that PWA would be geographically indigenous to regions with temperate climates given their non-pigmented skin colour. However, Buffon's future expeditions to non-temperate climatic regions made him to realise that PWA are not exclusive to temperate regions as he had believed. His first encounter with PWA was in Java, south-east Asia, where he met a community of exiled people - the *Chacrelas* [as the PWA were called]. He described them as being white and blond with weak eyes that cannot tolerate bright daylight. He added that whilst they walked with their eyes half-shut during the day, their visual acuity was remarkable at night time. On that occasion, Buffon concluded they must have emigrated from Europe.

Whilst on another expedition, Buffon encountered 'white-skinned' people whom the locals called *Bedas* on the Island of Ceylon; he buttressed his initial conclusion that they were shipwrecked Europeans, more especially as there were only a few of them. However, the experience of his expedition to Central America confounded his previous conclusions. In Panama, he had seen children with albinism born to dark-skinned parents. In his confusion, he speculated that albinism was a pathological disorder passed onto children from parents and

ultimately, a degenerative mutation. Buffon was convinced that anyone [including the French] could have albinism regardless of environmental climate given the backdrop of miscegenation. However, he still emphasised that he believed albinism was more prevalent in non-temperate zones. Buffon appended the adjective *Blafard* [meaning pale] as a collective social identity for all PWA, including other identity terms such as *dondos*, *nègre blanc*, *chacrelas*, and *bedas*. This term, *Blafard*, naturalised albinism but still made the phenomenon conceptually strange.

In his attempt to further humanise the PWA, Buffon physically examined a naked fifteen-year-old girl with albinism from Dominica Republic (Douthwaite, 2002). He recorded that she was shy just as any nude normally-pigmented human being would be if paraded in front of inquisitive eyes. He ascertained that she had perfect dentition and appealing curvatures of a grown woman, thus, implying that the girl was not without sexual appeal [like any other human female]. At this point in time, the PWA's former 'monster' social identity had started to erode, but not entirely. Buffon solidified his claim on the humanity of PWA when he discovered that a parent with albinism could produce a normally-pigmented child. However, the question of aetiology of albinism still remained largely unanswered.

Another French philosopher and member of the French Academy of Sciences, François-Marie Aroue known by his *nom de plume* as Voltaire, who had also attended the exhibition to examine the young boy with albinism from South America [although at a different location from Maupertuis and Buffon] vigorously criticised Buffon's philosophy on albinism.

In his publication on strange subjects, Voltaire (1768) repudiated Maupertuis' (1749) theory of accidentalism on two points of argument. Firstly, that the *nègre blanc* is a mutated variant of the white race, and thus, shares a similar genetic origin. Secondly, that albinism is a

biological link between the white and black race. Voltaire portrayed the boy with albinism as a fully grown midget; the pictorial representation of which was published in a 1745 Parisian tabloid article titled “*Relation touchant un maure blanc amené d’Afrique à Paris en 1744*”, that is, “Relation touching a white Moorish brought from Africa to Paris in 1744”. This depiction misrepresented the physical identity of PWA as monsters in two ways: firstly, as a strange being with unusual skin colour; and secondly, with atypical morphology. This fuelled Voltaire’s polygenist ontology that it is unacceptable to establish any genetic ancestry between the white and black man as proposed by Maupertuis’ theory of accidentalism.

To further dehumanise and de-categorise the PWA from the white race, Voltaire’s (1768) appositely titled *des monsters et des races diverses* [“monster of diverse races”] chapter invoked a neology from *nègre blanc* to *maure blanc* [Moorish white] with insistent emphasis that albinism is exclusive to the black race and by origin, from Africa. His literary justification was the dictionary meaning of ‘moor’ [black] during the enlightenment era (Johnson, 1755).

French philosopher Denis Diderot (1765) also submitted a rather disparaging treatise that further dehumanised the PWA in a somewhat ambivalent perspective. He pushed the agenda of white supremacy by positing that all *nègre* [black Africans] would have naturally been born white but for the effects of the tropical climate which blackens their skin colour. Furthermore, he described the *nègre blanc* [PWA] as a “stricken imagination of pregnant women” (Levy 2012, p. 80) to imply congenital deformity and defiance to the natural effects of the tropical climate. Diderot submitted that the PWA was as “pale as dead corpses” (Levy 2012, p. 80) and continued to represent the PWA as a monster. He further speculated that the PWA serving in the palace of the King of Loanga [as observed by Battel (1614)] were oracles who invoked spirits to endow the king with good health and long life.

While Buffon had made noble attempts to humanise the PWA in the spirit of fairness and equality, it sufficed to speculate that the travelogue accounts of other philosophers had been defamatorily far-reaching. As a matter of fact, I believe that Diderot's compendium may have laid the foundations that advanced the agenda for unfair social identities ascribed to PWA.

2.3.2 The role of symbolic interaction in the social misidentification of persons with albinism

The previous section outlined the ways by which explorers and colonisers in the Enlightenment Era used their opinions on albinism to create social identities for PWA that led to the accumulation of odd names. This section uses the ideology of symbolic interactionism to exemplify how social identities for PWA were created, passed down and embedded in languages of description.

The use of symbolic interactionism was considered to be consistent with Charmaz's "theoretical perspective that assumes society, reality and self are constructed through interaction and thus relies on language and communication" (Charmaz, 2014, p. 9). While the foundations of symbolic interactionism can be attributed to George Herbert Mead, it was one of his mentees, Blumer (1969) who established the tenets of symbolic interactionism as follows (p.2): (i) human beings act towards things based on the meaning that these things have for them; (ii) the meaning of such things is derived from, and rises out of the social interaction that one has with one's fellows; (iii) these meanings are reconstructed and conveyed through an interpretive process that has been situationally adopted by the person.

From the foregoing, it is plausible to infer that society as we know it, is socially constructed through the exchange of thoughts and ideas by the use of language in everyday interactions. In effect, these interactions shape societal attitudes and disposition meted to different social groups. This resonates with Benner's (1985) axiom that "No higher court for the individual

exists than meanings and self-interpretations embedded in language” (p.5). Thus, the presuppositions created by interactions and the attached meanings as conveyed by language continue to be a major determinant of social reality and identity of persons with albinism.

As earlier implied, the passing of time has bestowed varied modifications on people’s perception of albinism. Indicatively, these perceptions are rooted in the works of the philosophers mentioned in the earlier section of this chapter and how their expedition across Africa was instrumental in disseminating their ideas on albinism (Sandford, Thomson & Cunningham, 1841). Given that these philosophers, some of whom were actively involved in colonisation of African regions were regarded as highly scholarly and enlightened, their ideas and theories were deemed sacrosanct, undebatable and acceptable (Malcolmson, 2016). In essence, African natives felt the need to ground albinism in cultural beliefs as a means of explaining those acquired ideas and perceptions. This was perhaps the origination of various superstitious beliefs woven around persons with albinism as creatures of myth, all of which developed into dehumanising and disempowering stereotypes. The consequences of these superstitious beliefs about albinism are manifested through the mechanisms of labelling such as name-calling, social marginalisation and stigma.

2.3.3 Labelling as a mechanism for albinism stigma

Lemert’s (1972) conceptualisation of the labelling theory as “crude sociological determinism” (p.13) is based on two forms of differentness from normal societal expectations. Primary differentness refers to characteristics that are apparently aberrant to social norms, but do not confer a permanent manifestation of anomaly and thus, will not attract special attention. These types of differentness are usually informal and seemingly transient; for example, juvenile delinquency and speech disfluency [such as stuttering], both of which are expected to phase out with age (Cohen, 2014). On the contrary, secondary

differentness is an abnormal characteristic that is permanent and significant enough to assign an individual to a stigmatised group. Conditions such as blindness, leprosy, physical disabilities [including albinism] would be rightly placed under this category. Labelling and name-calling function as instruments with which aberrant individuals are identified, categorised and differentiated all of which ultimately lead to stigma.

Link and Phelan (2001) conceptualised stigma as an interplay of four components as illustrated in Figure 3. The first component is the categorisation of human differences into labels, that is, name-calling, which would seek to highlight an individual's differentness above the individual's humanity. An example of this is evident in the labelling of one's race as being white or black based on the colour of an individual's skin. In formal terms, 'white' means Caucasian and 'black' means African, African-American or both even though the mere categorisation of skin colour would already have placed one's racial distinctions before the actual content of one's character.

The second component of stigma is the association of labelled human differences with negative attributes, otherwise known as stereotypes. These stereotypes are usually rooted in cultural beliefs compounded by historical myths, and superstitions. It has been suggested that stereotypes are propagated to instil misconceptions of selfish political correctness by social and political actors (Bauer, 2013; Weber, Lavine, Huddy & Federico, 2014)

In the third component, labelled people are placed into social identities so as to accomplish some degree of marginalisation which consequently conveys a sense of misplaced identities of "us" and "them" (Devine, Plant & Harrison, 1999, p.1213), and a biased imbalance in the power dynamic of human interaction. In the fourth component, labelled individuals will experience self-devaluation, status loss and discrimination, all of which in addition to

marginalisation will form the pedestal for social injustices, as well as social and health inequalities and unequal health outcomes. Self-devaluation and status loss would imply that the stigmatiser regards the stigmatised as undeserving; this may explain the inhumane treatment of PWA by rapists and body-parts peddlers (Brown, 2008; National Organization for Albinism and Hypopigmentation [NOAH], 2007). Consequently, the inapt labelling of PWA, the construction of negative stereotypes for albinism, marginalisation and the unfair administration of social exclusion and discrimination limits accessibility of PWA to socio-economic opportunities such as education, employment, health, and social care.

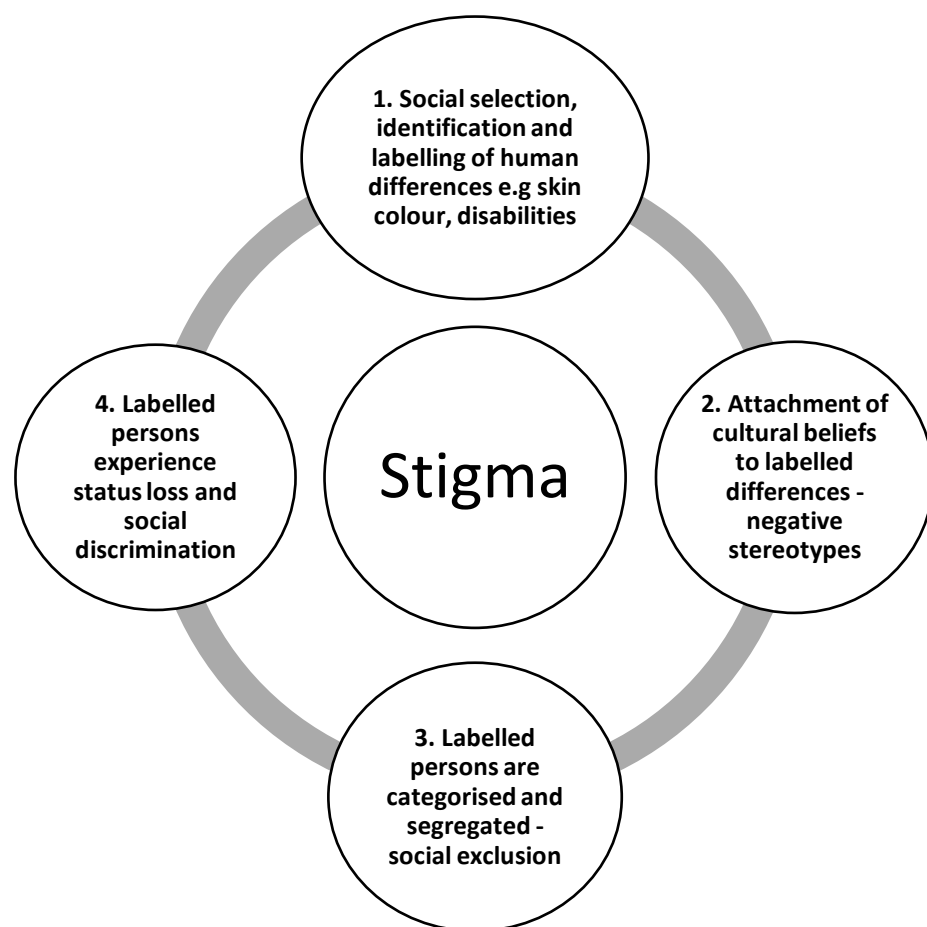


Figure 3: *Conceptual framework for stigma (Link & Phelan, 2001)*

In addition to the clinical morbidity of skin cancer and poor sight due to hypopigmentation which in itself already impairs the quality of life, the physical presentation of albinism further exposes PWA to stigma and societal intolerance. The theory of stigma as pioneered by Goffman (1963) elicits different facets of the stigma phenomenon. Goffman defines stigma as “an attribute that is deeply discrediting” and further states that stigma reduces its recipient(s) “from a whole and usual person to a tainted, discredited one” (Goffman, 1963, p.4; p.13). Goffman (1963) describes three types of stigma which include tribal stigma, which is passed down a family line and thus, devaluing such lineage; abominations of the body such as physical disabilities; and blemishes of character such as individual beliefs and preferences that may be seemingly deviant from social norms.

Jones et al. (1984) in their interpretation of Goffman's definition posit that stigma represents an association between an attribute and a stereotype. Thus, stigma can be alternatively understood as an attribute that associates a person to undesirable characteristics. Crocker, Major, and Steel (1998) affirmed that “stigmatized individuals possess (or are believed to possess) some attributes, or characteristics, that convey a social identity that is devalued in a particular social context” (p.505). Drawing on Link and Phelan's (2001) conceptual framework for stigma as presented in Figure 3 above, it becomes conceivable that stigma will pose emotional and psychosocial stress on PWA.

Labelling and name-calling contribute significantly to the stigmatisation of PWA in different African cultures, many of which are intended to be more pejorative than endearing (Brocco, 2015). In a study to investigate the acceptability of Tanzanians with albinism in South Africa, Ikuomola (2015a) reported that even though PWA may not experience any sort of hostility from white South Africans, nevertheless, they were called names such as colonial master,

white spy and black Afrikaner. This, he added, may be an indication of the undertone of racial discrimination still apparent in the country.

In the Central African Republic, PWA are called *mbunzu gozo*, that is, black eater of manioc, as an emphasis to the ridicule attached to their skin colour (Ogrizek, 1983). Imperato and Imperator (2006) reported that the Bamana and Maninka tribes in Mali refer to PWA as *gomblè* which literally means *red man*, in reference to their natural susceptibility to sunburn.

In Cameroon, PWA-labels vary with respect to ethnicity. To the Bamileke people of western Cameroon, individuals with albinism are called *meffu*, meaning *dead*, which suggests a mythical association of albinism with the mysticism of the deceased (Baker & Djatou, 2007). Other defaming social labels amongst the Bakweri and Pahoiun tribes of central and southern Cameroon include *mongou* - strange being; *nnanga kon* – ghost; *ko* - different being and *fogtab gab* - white chicken.

East Africa is documented to be particularly infamous for sub-human names for PWA, many of which have made societal integration increasingly difficult. Kiswahili names such as *zeru zeru* (ghost), *mzungu likode* (fake white person), *mbirimiru* (spotted skin) and *napwere* (wrinkly skin) (Braathen & Ingstad, 2006; Mulemi & Ndolo, 2014; Thuku, 2011) continue to devalue the humanisation of PWA.

In Nigeria, the Yoruba tribe from the south-west region calls PWA *afin* or *eni-orisa* that is “*he who belongs to the deity*” to imply sacredness to the gods (Olagunju, 2012). Due to the superstitious awe woven around their existence, communication and relationship with PWA is limited so much so that they are even accorded special funeral rites (Adelowo, 1990). In the Efik language of Akwa-Ibom and Cross-River States in southern Nigerian, a PWA is called *Afiamkpai* which means “*white man from the bush*” (Amer, Graham-Brow, Klaus &

Pace, 2012, p.65). Jake Epelle (2010), founder of the Albino Foundation (TAF) of Nigeria in an interview with the Daily Newspaper relayed that all ethnic tribes in Nigeria deride PWA. He added that the Igbos of eastern Nigerian refer to PWA as *ayarin*, meaning yellow skin; the Edos call them *ebo* [sacrificial] and the Hausas in northern Nigeria call them *bature-ntuda* which means fake white man, all of which are utterly disrespectful. These labels are symbolic mechanisms of social interaction that contribute to the perpetuation of stigma for PWA.

In a predominantly black-skinned society such as Nigeria (and sub-Saharan Africa as a whole), it is without any effort that PWA stand out as being conspicuously deviant from the normal expectations of physical appearance. Their physical difference coupled with various cultural myths on the aetiology of albinism form the basis for unfair societal treatment and dire psychosocial implications.

The impact of stigma on the accessibility of life opportunities for people with albinism in sub-Saharan Africa can neither be overemphasised nor under-estimated. Stigma to PWA spans a variety of domains which include education, employment, relationships, and access to healthcare and social welfare. From a factual point of view, the biological implications of their visual impairment and skin condition compel PWA to avoid outdoor activities that may expose them to deleterious effects of tropical sunshine (Brocco, 2015). The implication of which keeps them hidden from everyday communal interactions. In a complementary perspective, cultural definitions of albinism most of which are embedded in myths and superstition further contribute to their withdrawal from normal social life and engagements. Furthermore, the differentness in physical appearance and stigmatised social identities make PWA to withdraw from social spaces in an attempt to avoid undue public attention; and by so doing, they alienate themselves from society (Mulemi & Ndolo, 2014). From the foregoing, it sufficed to surmise that people with albinism experience bio-cultural exclusion.

2.4 Social construction of albinism across Africa

The representation of albinism across Africa differs according to respective cultural nuances. For example, the Venda tribe of South Africa believes that there is a snake inside a woman that helps to monitor and ensure safe delivery of the baby. However, the baby would be cursed with albinism if the mother comes in contact with a PWA during pregnancy (Baker, Lund, Nyathi & Taylor, 2010). Another very common misconception in South Africa lends strength to the belief that albinism is contagious. This may be attributable to the traditional segregation of people with albinism, especially as children are deprived of playmates and adults with normal skin colour will consciously avoid contact and communication with PWA (Onoja & Airahoubor, 2006; Wan, 2003).

The Shona tribe in Zimbabwe believes that the birth of a child with albinism (CWA) is a proof of the mother's infidelity with a malevolent spirit known as *tokolosh* (Bourdillon, 1987); whereas some other rural clans remain convinced that a baby with albinism is a punishment for past misdeeds by the parents (Baker, Lund, Nyathi & Taylor, 2010). Ackley (2010) reports that Isaac Mwaura of the Albino Association in Kenya stated that single mothers raised an estimated 90 percent of children with albinism living in the Lake Victoria region because the husbands believed the wives to have had sexual affairs with white men, alluding to the miscegenation theory of Comte de Buffon (1749).

These beliefs have fuelled infanticide and, in many cases, spousal separation, thereby leaving the mother to cater for the child as a single parent (Metcalf, 2003). The Tonga people in western Zimbabwe also contextualise albinism as the physical manifestation of water spirits capable of curing diseases and bestowing material wealth, as a result of which PWA have become a target for rape and ritual killing (Machoko, 2013). This belief is congruent with similar superstitions from Ghana, Cameroon, Benin, Burundi, and Tanzania. Within the last

ten years, there has been a widespread genocide of people with albinism and trafficking of mutilated body parts believed to convey magical powers. For this reason, people with albinism in the Lake Zone region of Tanzania and Burundi have become prey to traditional healers and witch doctors (Aquaron, Djatou & Kamdem, 2009; Stensson, 2008).

In Nigeria where this study was conducted, the myths about albinism are not much different from other African cultures. The Yoruba tribal belief holds that people with albinism are agents of the gods, sent as a punishment for ancestral misdeeds (Olagunju, 2012). As a consequence of this supposed supernaturality, the PWA's blood is therefore believed to be potent for longevity and money-making rituals; this bears a similar reflection with beliefs from Zimbabwe, Tanzania and Burundi. According to Achebe (1958), the birth of a baby with albinism in the Igbo tribe of eastern Nigeria is considered an abomination; and such a child would be left in the evil forest to perish, thus confirming the practice of infanticide as stated earlier on. The Hausa tribe in northern Nigeria have also been documented to practise infanticide due to the unacceptable appearance of a baby with albinism (Tremearne, 2014).

2.4.1 Impact of the albinism stigma on marital and household wellbeing

The possibility of romantic relationships and marriage appears to be a predicament for people with albinism. Due to the burden of stigma that their differentness confers on them, PWA have limited chances of marrying a normal pigmented individual. Thus, many PWA may be compelled to either stay single (Aleksandra, 2010) or marry a fellow PWA which will only strengthen the albinism gene to bear children with albinism (Gaigher, Lund & Makuya, 2000). Ikuomola (2015b) suggested that it may be relatively easier for a male with albinism to foster a romantic relationship and marriage to a normal pigmented woman, than for a female with albinism to a normal pigmented man. In his view, the gender preference often exposes the female with albinism to marital or partner abuse, especially if her [normal

pigmented] husband had married her out of favour or out of deceit as is the case in Besu's story (See Section 6.5.2).

In what may have been initially considered a fortunate situation where a person with albinism marries a normal pigmented individual, such marriages have been reported to experience difficulties, abuse and an eventual spousal separation (Baker, Lund, Nyathi & Taylor, 2010). Allen (2010) notes that in Uganda, "Fathers are likely to abandon or kill a child with albinism, sometimes along with the mother, based on either superstitions or suspicion of mother's infidelity, or from the stigma associated with having a PWA in one's family" (p. 10). This may account for why 60% - 70% PWA in Uganda are from single parents (Disability Support Uganda, 2016). This finding reflected the opinion of Barnes and Mercer (2005) that as a result of name-calling, people with albinism have been the cause of divorce in many of such families. An earlier documentary report by Metcalf (2003) relayed how a young Zimbabwean lady with albinism had got engaged to a *normal black* man. When she shared the news of her pregnancy, her fiancé's parents forced him to cancel the wedding because they were embarrassed to have a grandchild with albinism; the said lady had to return to her father's house to deliver the baby and live out her life as a single parent. Similarly, Kiprono, Joseph, Naafs, and Chaula (2012) in their study on the quality of life of PWA in Tanzania reported how much damage albinism can inflict on marriages and relationships. They sampled a total of 138 people with albinism, all of whom were eligible for marriage. Seventy-two (52.2%) were single, 39 (28.3%) were married, and 18 (13.0%) were either separated or divorced. Twenty of the 39 married respondents had problems with their partners because of their physical appearance. Similarly, 9 (50%) of 18 separated or divorced respondents reported that their skin colour was the main reason for separation or divorce.

The impacts of albinism on couples extend beyond the possibility of separation onto other aspects of household wellbeing. In cases whereby both parents are still together, abuse and neglect may be meted out to the partner with albinism or to the wife for giving birth to a child with albinism. A respondent in Masanja and Magembe's (2015) study recounted how her mother was always beaten by her father for bearing him a child with albinism. She further stated that her father did not visit the hospital when she was born and if not for her mother's strong Christian faith, she would have been killed or abandoned at birth. Another respondent, a male PWA with two children relayed how he could no longer provide for his family because he had to abandon his fishing business when abduction and ritual killing of PWA was widespread in east and southern Africa. Since he lost his financial capabilities, his [normal pigmented] wife left him, took with her one of their children who is normal skinned, leaving behind the other child who has albinism like himself. Not only did he lose his social status as a husband, it appears that he also would not be able to cater for his child seeing as his social environment did not enable him to search for jobs.

The case-study above suggests that stigmatisation of people with albinism may emanate right from within the home and perpetrated by family members. In light of this, PWA are well documented to experience shame and embarrassment from family members such that parents and siblings will avoid public appearances with their children with albinism and may not even enrol them in schools for fear of being bullied (Lund, 2001; Ndomondo, 2015; Onoja & Airahoubor, 2006).

2.4.2 Impact of the albinism stigma on education

Literature highlight the fear of contagion as a reason for society's unkind disposition towards children with albinism, which impacts school enrolment and active classroom learning participation. An early investigation by Ezeilo (1989) surmised that undergraduate students

with albinism (SWA) expressed more emotional instability than the normal pigmented students. The SWA in their views declared that other students actively avoided them and made them feel excluded from university life. The SWA added that society's unkind attitude to them might account for why they did not feel the need to make friends. Similarly, Metcalf (2003) relayed the experiences of a child with albinism who was placed at the back of the class because her pregnant teacher wanted to stay away from her as far as possible. The outcomes of this incident included poor academic performance as the girl could neither see the board [given her naturally poor sight] nor enjoy personal tutoring from her teacher; and poor psycho-social skills which can arguably inhibit self-development. Baker, Lund, Nyathi, and Taylor (2010) corroborated the findings of the aforementioned studies as their research revealed that SWA at the University of Venda in South Africa claimed that other students would not share academic and recreational facilities with them and avoided them at school events. In congruence with the findings in this study, the impact of stigmatisation on education for people with albinism extends beyond poor school performance to actually set out the pattern of disadvantage for the rest of their lives.

2.4.3 Impact of the albinism stigma on employment opportunities

Again, the fear of contagion and poor education adversely affect employment opportunities for PWA. Given that many PWA do not have access to quality education, as a consequence, they are not able to effectively compete and thrive in the job market. In addition, literature has reported many PWA who have endeavoured to acquire qualifications may not be considered eligible for white-collar job positions because the business success of the majority of corporate firms hinges on the physical appearance of staff members (Karl, Hall & Peluchette, 2013; King, Winchester & Sherwyn, 2006).

A study in North America submitted that 95% of working-age PWA admitted to having faced difficulties in securing employment because employers felt they were blind and would not be able to handle work pressure even after they had acquired prescribed glasses to improve eyesight (Wan-Kee-Cheung, 2001). In resemblance to other investigations, Baker, Lund, Nyathi and Taylor (2010) reported the experiences of a woman with albinism in Bulawayo, Zimbabwe who claimed that she attempted to run a groceries shop but was compelled to quit the business because no one would patronise her for fear of contracting albinism from the goods she had touched. This experience is also true for a Tanzanian respondent in another study who narrated that she lost her job as a housekeeper with an educated government staff couple when they decided to start having children fearing that her continued presence may cause them to have a child with albinism. She gathered her savings and opened up a kitchen but did not get customers and the business folded up leaving her in debts (Masanja & Magembe, 2015).

It is evident from the featured literature that experiences of PWA in the working environment within an African context may not be dissimilar from what is obtained in a developed region such as North America. A disabling and inaccessible work environment not only widens the gaps of inequities and inequalities but also strengthens the cycle of poverty into which many PWA are likely to be born. Nevertheless, this thesis acknowledges that the working experiences of PWA are likely to be positive in several first world countries such as the United Kingdom where recruitment practices are required by law to commit to diversity and inclusion (Home Office, 2018).

2.4.4 Impact of the albinism stigma on health and wellbeing

Several studies on skin cancer have reported that many people with albinism only come to present their cases at late stages of diseases at which time treatment would be invasive and

expensive (Ademola, 2015; Ademola, Olawoye, Oluwatosin & Iyun, 2010; Asuquo, Nwagbara & Omotoso, 2011; Mabula et al. 2012; Opara & Jiburum, 2010). Arguably, the stigma accorded to the physical manifestation of albinism could be a factor for poor healthcare seeking behaviour as observed amongst people with albinism. Within the context of a typical sub-Sahara African social environment, many PWA fear that they would stand out like *a sore thumb*, and that hospital staff may not attend to them warmly; these factors, therefore, discourage them from promptly seeking medical treatment (Ademola, 2015).

Healthcare seeking behaviour amongst PWA may also be discouraged if the disease they are to seek treatment for already has a stigmatised label, in which case would mean double stigma conditions for them. This is most observed amongst PWA with HIV infection because HIV/AIDS is a highly stigmatised and socially labelled disease in sub-Saharan Africa (Alonzo & Reynolds, 1995). Aluko-Olokun and Olaitan (2015) in their study to assess how effectively HIV-positive PWA make use of free and available antiretroviral therapy services submitted that out of 35 HIV-positive PWA enrolled, only one PWA attended HIV clinic. The study concluded that 34 PWA stayed away from the HIV clinic due to stigma.

Due to the fear of being labelled with a socially unacceptable disease, PWA further exposes themselves to grave consequences such as drug-resistant and preventable death as a result of treatment interruption or non-adherence with drug regimen (Kamaradova et al., 2016; Mprah, 2016)

2.5 Influence of the film industry on albinism stereotypes and social identity for PWA

Film industries around the world are important sources of family entertainment, education, information, propaganda, orientation, re-orientation and disorientation of historical, cultural, political and economic values (Shah, 2011; Weber and Silk, 2007). Not only do movies

create avenues for families to spend time together, but movies are also instrumental in creating, shaping and reinforcing perceptions for the society (Ahmed, 1992). Movies are characteristic for being influential on how the society behaves (Gunasekera, Chapman & Campbell, 2005). People latch on to acquired ideas from movies and use these ideas to create everyday impressions. Movie narratives create characters with idiosyncratic stereotypes; and since movies have become inherent in everyday life, people are usually not able to separate screen fiction from life reality (Goenka, 2015).

Bormann's (1985) Fantasy Theme Theory, also known as the Symbolic Convergence Theory presents a relevant theoretical framework that could be used to explain how the media [through movies in this case] inform human perception and behaviour towards albinism and PWA. Fantasy Theme Theory argues that a group or community can achieve widespread consciousness by the dynamic process of sharing fantasies, values and motives for human actions through dramatization (Bales, 1970; Bormann, 1985; 1972). Fantasy in this sense refers to "the creative and imaginative interpretation of events that fulfils a psychological or rhetorical need" (Bormann, 1976, p.434). According to Shields (2008), fantasies are borne through the narratives of storytelling which in modern time is shared through movies viewed by the society, the result of which is the creation of a rhetorical vision. A rhetorical vision contains many fantasy themes that characterise heroes and villains in dramatic actions. Within any given society, acquired rhetorical visions establish the culture, identity, and stereotypes which people subconsciously imbibe and recreate in everyday interaction (Littlejohn & Foss, 2011).

Foss (2009) notes that fantasy themes are comprised of three components: (i) the setting themes which depict the social environment where the action is taking place; (ii) the character themes which describe the actors or people in the drama, ascribe characteristics, qualities and

motives to them; (iii) the action themes which portray the dramatic roles and performances of the actors. These components of the Fantasy Theme Theory can be used to understand how international and indigenous film industries have contributed to the misrepresentation of albinism and people with albinism.

2.5.1 Hollywood and Western representation of albinism and PWA

Hollywood is the metonymy for the United States motion pictures industry. Hollywood is the world's foremost film industry and remains the most powerful influencer of popular culture through music videos, movies, cartoons, advertisement and animations (Scott, 2005).

According to Nash Information Services (2017), a website that tracks box office revenue, Hollywood has experienced steady growth in generated revenue, estimated at \$10.69 billion, \$11.29 billion and \$11.25 billion in 2014, 2015 and 2016 respectively - an indicator of movie viewership beyond localised American audience. Since 1912, several American movies have featured characters with albinism, all of which arguably represented PWA as villains or individuals with strange, fearful and evil characteristics.

For example, the "Fall of the House of Usher" (Cornman, 1960) was a horror movie based on a short story written by Edgar Allan Poe (1839). The movie tells of a character with albinism— Roderick Usher played by Vincent Price. The protagonist, Roderick was portrayed as a psychologically disturbed PWA with symptoms of photophobia, hypochondria, and anxiety. He lived alone in a dilapidated house which was seemingly haunted by the ghost of his deceased sister. The movie terminated in a scene in which his sister's ghost came to claim his life. In reality, Vincent Price does not have or possess any manifestations of albinism.

This movie presented archetypal features of a Gothic tale: tragedy, a haunted house, dreary melancholy, mysterious sickness, and self-exclusion. The settings, character, and actions of

the protagonist may have conveyed a misplaced notion that persons with albinism are physically repulsive, psychologically unhealthy, desiring solitude and distance from society.

Another example from that period is “Nosferatu the Vampyre” by Herzog and Gruscoff (1979) based on the legend of *Dracula*, which featured Klaus Kinski as Count Orlock. Count Orlock the main character was a vampire: a blood-sucking creature whose bed was the inside of a black coffin. He was physically personified as a rodent-like man, with large ears, bald head, hollow eyes, pale white skin, sharp teeth, and long fingernails. The vampire caused several unexplained deaths in his neighbourhood. In the ending scene, he had preyed on the wife of his housekeeper and as sunrays flashed on his skin, his body began to disintegrate into a powdery mist until he disappeared. Whilst the protagonist in this movie was not featured as an albino character, his nocturnal behaviour with respect to the avoidance of sunlight and the deleterious effect of sunshine on his skin [both of which are conventionally linked with albinism] could potentially influence public perception of PWA as individuals with sadistic tendencies.

In contemporary times, the characterisation of PWA in American movies still suffers similar misrepresentation.

“Powder” is a science fiction fantasy movie produced by Salva, Birnbaum, and Grodnik (1995). The movie featured Sean Patrick Flannery as a teenager with albinism who did not socially fit in. When his mother was pregnant with him, she was struck by lightning which made her go into premature labour; she died shortly after giving birth to him. As a premature baby with a strange physical appearance due to albinism, his father rejected him. He grew up in the basement of his grandparents’ farmhouse, in total oblivion of the outside world. After his grandparents passed away, child services committed him to foster care where he was

constantly bullied for his appearance. In addition to an unequalled intelligence quotient (IQ), he realised he possessed telekinetic and telepathic powers all of which he harnessed to excel at physics. Amongst his peers, he was feared and misunderstood because of his powers. After spending an unsettled teenage hood, he returned to his grandparents' farm. In the ending scene, he was struck by lightning while running and he disappeared in a blinding flash of light. Even though this movie did not portray the PWA as evil or sinister, it illustrated many details that allude to the unrealistic supernatural or mythical characterisation of persons with albinism which may influence the perception of people. The protagonist's transcendental metamorphosis at the terminal scene might as well reflect a common misconception in Africa that PWA do not die but simply disappear or vanish (Kromberg & Jenkins, 1997; Oduah, 2017).

Hollywood blockbusters such as *Star Trek Nemesis* (Barman & Baird, 2002), *Die Another Day* (Tamahori, 2002), and *The Matrix Reloaded* (The Wachowskis, 2003) have featured characters with albinism as evil and vengeful people.

Dan Brown's (2003) book "Da Vinci Code" was adapted into a movie by Howard and Goldman (2006) with the same title. The movie featured Paul Bettany as Silas, a masochistic assassin with albinism employed by the fictional *Opus Dei* society in the Catholic Church to murder anyone who can potentially reveal a revered church secret. Before the cinema release of the movie, The National Organization for Albinism and Hypopigmentation (NOAH) made several unsuccessful attempts to reach the directors not to bleach Silas' hair or make his eyes red. After the release of the movie, members of the albinism community in the United States were disappointed at how the PWA was portrayed. During an Associated Press interview on 16 May 2006, the President of NOAH Mike McGowan (2006) bemoaned the filmic misrepresentation of PWA when he stated that:

“The Da Vinci character is just the latest in a long string. It will be the 68th movie since 1960 to feature an evil albino. The problem is there has been no balance. There are no realistic, sympathetic or heroic characters with albinism that you can find in movies or popular culture. We understand that millions read it and when they go to the movie, they're going to want to see the albino monk-assassin. It's the cumulative effect of having one evil albino character after another that was disturbing to me”.

The Cable News Network [CNN] (2006) reported that following its original publication in English Language in 2003, “The Da Vinci Code” has been adapted in forty-four languages with over 60.5 million purchased copies. Consequently, due to an unprecedented global viewership of the film adaptation, the movie recorded a revenue of \$217,536,138 in the year of cinema release.

World-renowned Harry Potter (Rowling, J.K, 2001-2011) movie series made for children audience was enjoyed for its fantastic and magical narratives. The evil overlord Voldemort, played by Ralph Fiennes, had an insatiable thirst for death and destruction and inspired fear even amongst his loyalists. Physically, he was presented as pale white skinned, bloodshot eyes, visible veins, bald head. The majority of these physical characteristics are similar to those of PWA. Bearing in mind that the movie series was designed to entertain children audiences, it is plausible to speculate that millions of children may have developed an appreciable sense of dislike for whoever had a similar physical appearance as Voldemort. Speculatively, this highlights how the imaginative perception of people could be potentially influenced to bear a misconstrued image of PWA.

A more recent production “Logan” (Mangold, 2017) follows the X-Men series of mutated human beings with supernatural powers. This installation centres on Logan (played by Hugh

Jackman) also known as the Wolverine whose healing abilities had begun to diminish as a result of which he has physically aged. Logan's loyal ally, Caliban, was personified as a mutated individual played by Stephen Merchant. Caliban's character was characteristically bald-headed, pale white skin, sunken bloodshot eyes with an eerie personality. Caliban presents as physically unattractive, and he walks about bent over as if he is in a constant state of fear and insecurity. When outdoors, Caliban is clad from head to toe and would wear dark glasses and hat to protect his fragile skin from sunshine. We were shown that the slightest exposure of his skin to sunrays will cause the skin to burn and corrode in a similar semblance with PWA when they become over-exposed to sunshine and consequently develop skin cancer. I wish to state here that Caliban in the movie was neither a villain nor a PWA.

However, whilst the natural need to protect his skin from sunshine is realistically true with albinism, Caliban was portrayed as other worldly, undesirable and sickly. These attributes, if not carefully understood, have the potential to influence public perception of PWA.

Similarly, film industries outside Hollywood have also produced movies which have featured characters with albinism in degenerate roles. In Germany, Jürgen Goslar and Scott Finch (1970) produced "Albino" which centred on an albino terrorist who had raped and murdered his fiancée. With the police hunting him, he became a fugitive who perpetrated evil along the way as he made his escape. Due to an encouraging viewing rate, the movie has seen multiple remakes with macabre titles such as "Death in the Sun" and "Whispering Death". The character with albinism was played by Christopher Lee who in real life does not have albinism. This movie characterised the PWA as violent and sinister, a fact which makes a justifiable reason to speculate that the viewers of that time may have regarded real-life PWA through similar lenses.

A 1957 Swedish drama-fantasy film “The Seventh Seal” by Ekelund and Bergman (1957) featured Bengt Ekerot as a character with albinism who played ‘Death’. Death in this movie was personified as a bald, pale-white skinned man with sunken bloodshot eyes clad in a black robe. Death had started claiming people’s lives through a plague, and a knight had challenged him to a game of chess in an attempt to compel death to spare the survivors of the epidemic. Death won the game and ravaged what was left of the community. In real life, Bengt Ekerot does not have albinism; however, it appears that the producers of the movie felt that only a character with albinism could convey such sense of fear and destruction.

I wish to draw the mind of the reader to the fact that none of the albino actors mentioned above have albinism. Their physical appearance in these movies was made possible by theatrical make-up, costume, and special effects which were made easier because of their Caucasian skin. Based on this premise, these actors could not have been truly aware or representative of what it means to have albinism.

2.5.2 Nollywood representation of albinism and PWA

Moving past Hollywood and the Western motion picture space, the Nigerian film industry also known as Nollywood has contributed significantly to how albinism and persons with albinism are inappropriately perceived and socially identified (Mbogo, 2008; Obonyo, 2008; The Witchcraft and Human Rights Information Network, 2013).

Nollywood is the largest film industry in Africa with an expanded viewership of Nigerians in the diaspora through various YouTube channels. Nollywood produces an average of 50 movies per week, a feat that makes the Nigerian film industry to outrank America’s Hollywood and India’s Bollywood in terms of output (Clayton, 2010). Statistics reported by Moudio (2013) indicated that Nollywood provides employment for over one (1) million

Nigerians and generates an estimated annual revenue of \$590 million. Undoubtedly, Nollywood movies provide the largest avenues to disseminate and promote Nigerian culture, values, and beliefs (Olaiya, 2013).

Persons with albinism are seldom featured in Nigerian movies. Arguably, they are considered inefficient and consequently excluded from the entertainment workforce for reasons that are not far-fetched (Epelle, 2017). The weekly Nollywood production output stated above suggests that the industry is fast-paced and competitive for viewership. Thus, producers are more likely to employ actors with efficient capacities. However, considering the PWA's visual and dermatological impairment, script reading is likely to become problematic, and producers may be compelled to restrict the albino actor's featured performance to indoors and night scenes (Mogbogu, 2009; Olaiya, 2013). The succeeding part of this section examined three movies which have featured actors with albinism in an attempt to delineate how albinism and the PWA was portrayed.

“Ti Oluwa ni ile” [The Land belongs to God] is a classical Yoruba movie produced by Tunde Kelani (1993). Tunde Kelani is arguably the most illustrious movie producer from the south-west region of Nigeria. His movies are notable for outstanding quality and storylines that highlight the corrosive influence of Western civilisation on indigenous African culture and social vices such as corruption, avarice, moral compromise, and political misconduct. “Ti Oluwa ni ile” tells the story of a group of land speculators who enlisted a corrupt traditional chief to sell an ancestral land fraudulently to a businessman who plans to build a petrol station in an honest attempt to improve the business prospects of the community. Against the will of the monarch, the land was sold. As a consequence, ancestral gods of the land started waging gruesome deathly retribution on everyone who was involved in the transaction. In a means to escape pending death, the corrupt traditional chief who coordinated the sale of the

land left the community in search of spiritual help. After a fruitless sojourn, he decided to commit suicide in a forest. As he was about climbing a tree to hang himself, he hears someone shouting for help – three men had abducted a PWA in order to kill him and use his body parts for money ritual. The chief fought the kidnappers off and rescued the PWA. A friendship ensued between them, and after explaining his ordeal, the PWA helped the chief to find temporary relief from impending death. Two relevant points of notes are highlighted by the movie synopsis: (i) the movie epitomises a PWA as being able to apportion wealth; (ii) the movie validates a PWA as being spiritually gifted.

Although Tunde Kelani (1993) had used this movie to awaken societal consciousness to the ills of corruption and to reinforce Yoruba traditional beliefs in existential gods, he did not make any conscious attempt to rebut the myth of the PWA's supernatural abilities.

Tijani's (2017) Yoruba comedy "AAA" follows the story of three friends. The three of them had individual businesses none of which was doing well. They consulted a witch doctor to help them increase customer patronage. The witch doctor instructed them to go get a PWA and gave them the charm to make the PWA submissive to capture. They set out in search of a PWA, got one, hypnotised him with the charm and took him to the witch doctor. The witch doctor murdered the PWA and made a concoction with his body parts which the three friends ate. Shortly afterward, each of their businesses started to experience unprecedented success. Eventually, they were all meted with judgement for their evil deed.

Again, here is another Nollywood movie that portrayed the PWA as a spiritual conveyor of wealth. Not only does this validate the stigmatisation of PWA in contemporary African society, but it also makes it conceivable for evil-minded people to target the PWA for ritual purposes.

Another recent Yoruba movie, “Kodi ologbon aye [Kodi the wise one]” (Adebayo & Adebayo, 2015) centres on Kodi, the village jester. Due to his lowly position, he was always disrespected and ridiculed by the villagers. Kodi realised that if he was wealthy enough, he would be able to rise above societal barriers. In his frustration, he looked up to the sky and shouted to the gods for help. Later in the night, two ladies with albinism appeared to him. They told him they were oracles sent by the gods. They instructed him to give them some money, which they would share with other albino oracles in Togo. They assured him that the money would be multiplied and returned to him. Kodi obliged them. In the coming days, the magic began to manifest, and Kodi became wealthy. Worthy of note is the fact that the “albino oracles” in this movie made mention of some sort of spiritual engagement with other albino oracles, citing Togo, another West African country. This movie appears to propagate the albinism stereotypes of being oracles and bringers of wealth. In a similar manner as the previously mentioned movies, PWA are stereotypically misrepresented as creatures of myth and magic.

I wish to state here that unlike Hollywood, the characters with albinism featured in the examined Nigerian movies are actual PWA. It sufficed to state that their participation in such misrepresentative roles is an antithesis to the true nature of albinism. Nevertheless, I do understand that given the poor socioeconomic status of PWA in Nigeria, being featured in a movie is considered an opportunity for income and perhaps fame, even if the role is contradictory to one’s ethos.

Arguably, these Nollywood movies based their representation of albinism on Yoruba mythology. In his treatise on myth and African literature, Soyinka (1976) theorised that aberrant pregnancy outcomes such as albinism, hunchbacks, and cripples are unintended products of *Obatala*, the Yoruba god of soul and purity. *Olodumare*, the Yoruba sovereign

god of creation tasks Obatala with the job of moulding human form. *Obatala* is believed to be a habitual alcoholic. In his drunken state, he is believed to make mistakes while moulding prospective human beings and *Olodumare*, bound by his duty of creation breathes life into all human forms. However, *Olodumare* in his benevolence bequeaths *Obatala*'s 'creation mistakes' with spiritual gifts that would forever grant them direct access to the supernatural realm, thereby, making them special and unique than regular human beings. Therefore, the Yorubas of south-west Nigeria refer to PWA as "*eni orisa*", that is, a person who belongs to the gods. This mythology arguably explains why PWA are perceived as spiritually influential. Many Nigerian myths are transnational and may have similar narratives in other African countries. If this is a valid argument, then, *Olodumare*'s compensational gifts have endangered PWA rather than preserve them because sociocultural belief in this myth continues to predispose PWA to kidnap, mutilation and murder as reported in Mali, Senegal, Tanzania, Burundi, South Africa, Zimbabwe and a host of other African nations (Imperato & Imperator, 2006; Ikuomola, 2015; Larson, 2011). This provides an empirical understanding of how the social identity and social mobility of a vulnerable group are both unfairly constructed and limited because of myth and cultural stereotypes.

These sociocultural representations in Nigeria contribute to the stigmatisation and social exclusion of PWA. Nigerian society appears to regard the individual as a derivative of his/her condition. The dehumanisation of an individual with albinism has led to a PWA being treated based solely on the appearance, with disregard for the eye and skin impairment that constitutes actual disabilities. Additionally, PWA are regarded as spiritual beings rather than disabled individuals who in actual fact require appropriate disability support. This may also explain why the term "*albino*" is most commonly used than "*person with albinism (PWA)*"

and the consequential absence of disability support for individuals with albinism as they pass through social phases of life from childhood into adulthood.

Admittedly, Hollywood's representations of albinism and PWA differ from how they are portrayed in Nollywood. Western film industries exemplify the PWA in the context of diverse adverse behavioural tendencies, whereas, Nollywood's representation is more spiritual. Perhaps this is because in Nigeria and Africa at large, daily social transactions are rooted in trado-cultural foundations (Iheanacho, 2018). At this juncture, it sufficed to state that regardless of the locale of the movie industry, there is a unifying theme of differentness, oddity, myth, and negative stereotypes whenever characters with albinism are featured.

2.6 Albinism as a disability

As earlier established in this thesis, albinism constitutes visual and dermatological impairments in addition to an unusual physical appearance. The WHO (1980, p.27) defines an impairment as “loss or abnormality of psychological, physiological, or anatomical structure or function” of a bodily organ. For all PWA, the absence of the melanin pigment is a physiological impairment which causes numerous inter-related defects of the eye.

Hypopigmentation makes the iris translucent, which disenables the eye from filtering light (Grønskov, Ek & Brondum-Nielsen, 2007; King & Summers, 1988). As a consequence, PWA are colour blind and are unable to maintain visual focus. Furthermore, the fovea which is the part of the retina responsible for visual acuity is underdeveloped due to congenital misrouting of optic nerves connecting the eye to the brain (Bouzas, Caruso, Drews-Bankiewicz & Kaiser-Kupfer, 1994; Gupta, Yonekawa, Jonas, Orlin & Chan, 2016). The anomaly of misrouted optic nerves worsens the functionality of the eye by causing nystagmus, that is, the rapid, uncontrollable movement of the eye often experienced by PWA.

For PWA, skin functionality is significantly compromised because of hypopigmentation, especially in tropical regions. For the skin, melanin functions as an absorbent pigment that constitutes a barrier to reduce the penetration of ultra-violet rays from sunlight (Kaidbey, Agin, Sayre & Kligman, 1979; Morison, 1985). Hypopigmentation exposes the skin to the deleterious effect of the sun (Brenner & Hearing, 2008). For PWA, unchecked exposure to sunlight over time often results to squamous cell carcinoma, a type of skin cancer around the head region (Lookingbill, Lookingbill & Leppard, 1995; Yakubu & Mabogunje, 1993). In the preceding statements, I have attempted to describe how the physiological consequences of albinism limit the full functionality of the eye and skin, thus, fitting the WHO's (1980) definition of impairment. Having established this, a point to clarify here is that visio-dermatological impairment in PWA does not necessarily indicate the presence of a disease.

From an African perspective, PWA are not considered disabled because disability immediately connotes a physical appearance of anomalies such as loss of motor functions, spinal cord injury, loss of limbs and the consequential use of wheelchair (Goodman, Dornbusch, Richardson & Hastorf, 1963; Richardson, Goodman, Hastorf & Dornbusch, 1961). Admittedly, the true meaning and scope of disability have evolved by means of several modifications (Wood, 1975). Nevertheless, this study adopted the WHO (1980) definition of disability as “any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (WHO, 1980, p.28). If this definition is applied to PWA, then it is plausible to argue that functional and social consequences of visio-dermal impairment constitute significant restrictions to utilising chances for better life opportunities which effectively make albinism a disability. For instance, all participants in this study identified visual impairment as the primary obstacle to full learning participation in school, and as a consequence, the majority of

participants performed poorly in school. Poor school performance translated into poor grades and reduced chances to pursue higher education that would have otherwise equipped them to be competitive and eligible for professional employment opportunities. Participants also identified the inability to maintain visual focus and visual stability as a discouragement from pursuing marketable careers such as finance and accounting, engineering and medical sciences. Similarly, impaired skin condition translates into a natural avoidance of exposure to sunlight and the consequential lack of vitamin D in the body system thereby causing poor bone development as is characteristic with many PWA in Nigeria (Hermansky & Pudlak, 1959; White, Witkop & Gerritsen, 1973).

Visio-dermal impairment and associated disability is a life-long reality for PWA.

Incidentally, there is a scarcity of studies on visual rehabilitation for PWA. In an attempt to increase the quality of life for PWA, few studies have reported improved visual acuity for PWA with the use of telemicroscopic apparatus fitted into prescription glasses. In their retrospective study that sampled 77 patients with albinism, Pereira, Araujo and Patuzzo (2016) reported that all patients gained improved vision after rehabilitation with Galileu 2.8x optical device, and thus, recommended the device as most preferable for the best visual outcomes and most beneficial when used early as from childhood. Even though the findings of Pereira and colleagues remain invaluable to the albinism cause, the authors have not quite stated the availability and affordability of the Galileu 2.8x optical lens.

The Galileu 2.8x telescope is a high definition optical lens specially designed for surgeons and astronomers whose jobs require detailed vision (Exam Vision, 2019). The device is an exclusive product with a minimum purchase price of £479 and no sales outlet in any African country. My argument here is that while the device has been proven to significantly improve

sight and vision for PWA, it remains unaffordable and unavailable to the average PWA in Nigeria.

Beuschel and Todorova (2016) treated an infant girl with albinism with rigid iris-print contact lenses manufactured by Swiss optical enhancement corporation - Falco-Linsen AG. Over a period of three years, the study confirmed that the girl could maintain focus and accommodate vision to a considerable extent, thus improving visual development. In similarity with Pereira and colleagues (2016), Beushel and Todorova (2016) recommended that visual rehabilitation for PWA is best adapted and tolerated during childhood. However, as with the Galileu 2.8x optical lens, the Swiss iris-print contact lens remains unavailable and largely unaffordable to PWA in Nigeria. Even though the authors acknowledged that the iris-print contact is permeable thus allowing oxygenation of the eye, the study lacked information on how the authors managed the associated difficulties of wearing contact lens, especially for a child. Beushal and Todorova (2016) echo the findings of Omar, Idris, Meng and Knight (2012) who had adopted a similar procedure to improve the visual stability of a 21-year old Asian woman with albinism by using tinted iris-contact lenses. This strengthens the evidence that coloured iris contact lenses can improve vision for PWA across a wide age range. Having stated this, there still exists a lack of information on the ecological adaptability and tolerability of tinted iris contact lenses for PWA in an environment characteristic of constant sub-Saharan dust and intense tropical sunshine such as Nigeria.

Having established albinism as a disability, it was considered relevant to explore the extent to which visio-dermal impairment limits human capacity for PWA. In the context of social experiences, the WHO (1980) defined a handicap as “a disadvantage for a given individual resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual” (p.

181). This definition implies that social and cultural factors can constitute a handicap for people with disabilities as is observed in the findings of this study. Regrettably, the literature on the social experiences of PWA in Nigeria is scarce. However, continental and transcontinental studies referenced in the earlier section of this chapter suggest that PWA are socially disadvantaged. Nevertheless, the findings of this study revealed that PWA in Nigeria are excluded from active learning participation in childhood and employment in adulthood because of the unfair configuration of social institutions. Thus, the WHO's perspective on disability and the social model of disability both provide a framework with which it can be argued that albinism constitutes a disability as well as a handicap given the complexity of physiological impairment and the spectrum of social exclusion that limit the social capacity of PWA in Nigeria (United Nations, 2017a).

2.7 International and national responses to the plight of PWA

2.7.1 The United Nations approach

The United Nations [UN] (2017b) recognises the severity of the interrelated forms of violence, discrimination, and stigma faced by PWA globally. Following media reports on albino brutality across Africa which was initiated by Tanzanian investigative journalist Vicky Ntetema in 2008, the Office of the United Nations High Commissioner for Human Rights (OHCHR) considers PWA as disabled and vulnerable, deserving of special needs and human rights protection especially women and children with albinism (International Federation of the Red Cross and Red Crescent Societies [IFRC], 2009). In its resolution to promote and protect the rights of PWA, the UN (2013a) through its Human Rights Council highlight eight mandates, out of which three were assigned to governments of member countries (p.2):

- (i) Urges States to take all measures necessary to ensure the effective protection of persons with albinism, and their family members

(ii) Also calls upon States to take effective measures to eliminate any type of discrimination against persons with albinism, and to accelerate education and public awareness-raising activities;

(iii) Invites States, in collaboration with relevant regional and international organizations, to promote bilateral, regional and international initiatives to support the protection of persons with albinism;

In a report following the unanimous adoption of the resolution, the UN (2013b, p.17) further recommended that member countries should:

(i) Address the root causes of attacks and discrimination against persons with albinism, notably by proactively combating superstition and stigma vis-à-vis albinism, including through education and awareness-raising campaigns

(ii) Adopt firm measures and policies to address the multiple and intersecting forms of discrimination affecting persons with albinism, including by ensuring they have adequate access to health care, social services, employment, and education

(iii) Develop national institutional mechanisms for the protection and promotion of rights of persons with albinism, including by ensuring that national human rights institutions effectively address the human rights situation of persons with albinism

For task monitoring and compliance purposes, the OHCHR requested member countries to submit a report on the status and treatment of PWA and implementation strategy for achieving the aforementioned mandates. No response was received from the Nigerian Government regardless of the fact that the highest prevalence and incidence of albinism in the world is from Nigeria.

Intensifying its effort to raise global awareness about albinism and PWA, the General Assembly of the United Nations (2014) proclaimed 13 June as International Albinism Awareness Day, with effect from 2015.

2.7.2 The Response of the Nigerian Government

Even though the OHCHR did not receive any response from the Nigerian Government, it is note-worthy to state that The Federal Government of Nigeria had already proposed a National Policy on Albinism in Nigeria (NPAN) through the Federal Ministry of Education (FMOE) one year ahead of the United Nations Human Rights Council resolution. The NPAN is a multi-sectoral approach aimed to “improve the status of PWA by harnessing their full potential and guaranteeing equal access to education, social, health, economic and political opportunities” (FMOE, 2012, p.2). The NPAN (and implementation guidelines) was developed in 2012, the central focus of which was “to mitigate the learning challenges faced by PWA and create educational access” (FMOE, 2012, p. ii).

Given that the origins of social misidentification and societal unfairness experienced by PWA can be fundamentally attributable to widespread lack of accurate knowledge and information on albinism, it was logical for the FMOE to be the delivery mechanism for the policy.

Admittedly, this policy was a well-intended approach to ensure social equity for PWA by mainstreaming albinism into every sector of development, with complementary plans to establish two resource centres under co-partnership with TAF for strategic implementation. However, the findings of this study necessitated an implementation analysis of the NPAN given that PWA continue to experience multiple realities of social injustices in Nigeria.

The policy is laudable for its clearly stated rationale, vision, mission, goals, and objectives; however, its targets and outcomes are self-limiting and inefficient. For example, the policy

targeted to achieve 50% improvement in areas of providing health and social care services; quality learning conditions; and social justice and human rights protection for PWA in Nigeria by 2020, which is eight years following the policy validation. In addition, the policy set to increase societal awareness against socio-cultural discrimination and stigmatisation of PWA by 20% in 2020. In political calendar, eight years equal two tenures for any elected national administration, which in my opinion is an unnecessarily long period for a ‘fair and just’ government to implement a much-needed policy. Given that there is an estimated 6,200,000 million PWA in comparison with 179,800,000 normal-pigmented people in Nigeria, one would have expected that achieving set policy targets for a fractional number of people such as PWA would be considerably prompt.

The implementation guidelines for the NPAN proposed the actualisation of the following outcomes as presented in Table 2 below:

Table 2: Extracted deliverables from the National Policy on Albinism in Nigeria

National Policy on Albinism in Nigeria: implementation guidelines (FMOE, 2012, p12-17)		
Deliverable	Timeline	Purpose
Establishment of The National Agency for Albinism and Hypopigmentation	2014	National coordinating resource centre
National Albinism Centre	2014 - 2016	Research centre: provision of evidence for policy improvement

Build capacity of health workers	2013	Increase skills and knowledge of medical and care practice for better clinical management of albinism
Nationwide provision of free skin and eye care and treatment	2013 - 2014	Improve and sustain the health of PWA for better personal and social productivity
Development of albinism contents into Basic Education Teacher's guide	2012	Build the capacity of teachers to support learning for PWA
Integrate albinism into National Policy on Education	2012 - 2013	Improve the quality of education and learning for PWA across all levels of education
Nationwide advocacy to correct bias and myths on albinism	2013 - 2016	Modify societal perceptions of albinism and PWA
Provide employment for PWA in both public and private sector	2013 - 2016	To allow social inclusion and socio-economic improvement

Source: National Policy on Albinism in Nigeria: implementation guidelines (FMOE, 2012, p12-17)

As of the time of completing this study in August 2019, none of the proposed deliverables in the NPAN implementation guidelines have been achieved, which translates into seven years of policy ineffectiveness. For example, in September 2017, online and tabloid media were inundated with the story of a man with albinism who after successfully completing all required trainings and assessment, was refused active employment by the Nigeria Police

Force (The Albino Foundation [TAF], 2017; British Broadcasting Corporation [BBC], 2017). This news negates one of the deliverables of the NPAN and further indicates the widespread exclusion of PWA from employment, more so, in public service which is regulated by the Federal Government of Nigeria.

The ineffectiveness of the NPAN can be attributable to the lack of legislation to enforce its nationwide implementation. The bill for an act to establish a National Agency for Albinism and Hypopigmentation as proposed in the policy passed its second reading at the lower chambers of the Nigerian parliament on 19th of January 2017, the report of which was subsequently approved to be presented to the higher chambers for legislative consideration (Pulse News Agency, 2017). The report was scheduled to be reviewed on 31st May 2018 and considered for further approval by the Senate (National Assembly of the Federal Republic of Nigeria [NASS], 2018). At the time of completing this thesis, there was no accessible public information to confirm if the review was conducted as scheduled.

In addition to the slow development of the policy since its proposal in 2012, the bill to implement it has been criticised for not being truly inclusive (Adetula, 2017). Critiquing the report, it was observed that there was no [provision] for a PWA to be appointed as a member of the governing board. Adetula (2017) argued that it is essential to the interest of the albinism community that a PWA is a board member, as this will promote true representation. He speculated that the board membership would comprise individuals who are not genuinely sympathetic to the albinism cause and may otherwise act disconnectedly from the central purpose of the proposed agency. In light of this, he recommended that the proposal for board membership be amended to comprise individuals who have shown doubtless support to the albinism cause outside the political arena. Another limitation to the bill is that there is no provision to criminalise unjustifiable exclusion of PWA from public and private employment;

thus, there is no motivation for employers to adhere to the ideology of non-discriminatory recruitment practices. Ultimately, whilst NPAN and the bill are commendable efforts to promote social justice and equality for PWA in Nigeria, its slow development and lax implementation strategy may mean that there is no imminent respite from unfair societal treatment.

2.7.3 Discrimination Against Persons with Disabilities (Prohibition) Act, 2018

The efforts of the Albino Foundation in championing the cause for social inclusion, social justice and equality for PWA yielded a more positive response from the Nigerian government. On the 23rd of January 2019, the bill prohibiting discrimination of persons with disabilities (PWDs) was signed into law by President Muhammadu Buhari. The Discrimination Against Persons with Disabilities (Prohibition) Act 2018 defines a PWD as a “person with long term physical, mental, intellectual or sensory impairment which in interaction with various barriers may hinder their full and effective participation in society on equal basis with others” (p.19). This definition of a PWD offers full coverage for PWA because of the life-long visual and dermal impairment characteristic with albinism.

The Act stipulates structural and social adaptations to improve accessibility for PWDs across all areas of the built environment, including public buildings, roads, and parking spaces. In addition, Sections 17-20 in the Act makes provision for free education [to secondary level] and educational assistive devices especially for children who are blind, deaf and with multiple disabilities. Also, the Act forbids the exclusion of PWDs from employment on the basis of disability and stipulates that all public organisations should allocate five percent of employable human resources to PWDs with suitable qualifications. In terms of health, the Act guarantees unencumbered access to healthcare without discrimination to PWD and offers free health and medical care to only people with mental disability (Section 21 & 22). The Act

allows the maximum of a 5-year transitional period for adjustments to be made across all sectors country-wide to ensure full implementation and compliance. Contravention of the stipulations in the Act is punishable by law in the form of being charged to pay a fine, or imprisonment or both. In order to ensure compliance, Part VII of the Act makes provision for the establishment of The National Commission for Persons with Disabilities. The Commission is tasked with issuing compliance orders to deterring organisations and providing access to legal redress for PWDs who may have suffered discrimination to access life and social opportunities.

Admittedly, the Act is a commendable and progressive step to alleviating the plight of PWDs and by extension, PWA in Nigeria. However, the extent to which it is particularly advantageous and effective in levelling the playing field for PWA is not without limitations which I have attempted to critique in two ways.

Firstly, there is no consensus in the Act for the Commission to conduct a thorough nation-wide census in order to enumerate the disabled population and collate demographic information of PWDs in Nigeria. The implication of this oversight is likely to result in missed cases, and lack of valid metric data on the various forms of disabilities in need of interventions. Thus, this form of inadequacy has the potential to hinder the Nigerian Government in providing necessary and adequate resources to achieve the goals of the anti-discrimination legislation.

Secondly, the Act is light on the specificity of healthcare and social rehabilitation made available to PWDs. With respect to PWA, albinism and its accompanying visual impairment are primarily diagnosed at birth. If nothing at all, ensuring regular access to subsidised [if not free] eye care and visual aid services from childhood would more than any other intervention

allow the CWA to participate more inclusively and productively in school (See summary of recommendations in Table 7, Chapter 9). Expectedly, a productive school learning experience increases an individual's potential to gain the appropriate qualifications that are required for medium-high income employment and positive life outcomes.

The sum of my argument here is that the ultimate goal of The Discrimination Against Persons with Disabilities (Prohibition) Act 2018 to ensure equality is likely to be rendered unachievable without firstly tackling the underlying inequities that drive the perpetuation of social inequalities and resultant injustices that PWA [and by extension other PWDs] continue to encounter in Nigeria.

2.8 Summary

This chapter has not followed the conventional systematic review of literature common to scholarly work. Instead, in line with the methodological framework of constructivist grounded theory, extant literature has been reviewed to present themes that bear relevance to the substantive theory that has emerged from the findings. The literature review identified the history of social constructions for albinism and PWA, and how said history has influenced contemporary perception of albinism. Following this, the framework for stigma was used to conceptualise how the perception of albinism is being used to effectuate stigma in terms of pejorative labelling and stereotypes for PWA. Also, the chapter has presented synopses of movies from around the world to exemplify the potential contribution of motion picture industries to how albinism and PWA are symbolically and inappropriately represented. The latter sections in this chapter examined the ways by which albinism has attracted humanitarian and legislative attention internationally and in Nigeria.

Admittedly, the expanse of literature on the subject matter as presented in this chapter paints an undeniably compelling picture that epitomises the realities of having albinism especially in sub-Saharan Africa. However, the gaps that were identified in the reviewed literature border on the paucity of information on how to theoretically capture and qualify the realities of having albinism, especially within the context of a black African population. The argument here is that it is only when a phenomenon has been given a name through scientific means that one can only begin to explore viable strategies to address it appropriately and effectively (Hempel & Oppenheim, 1948; Strevens, 2008). Otherwise, a phenomenon such as the realities of having albinism will continue to manifest in outcomes with adverse implications for the health, wellbeing and social security of PWA. Therefore, these identified gaps justified the need for this study to be conducted.

Chapter 3: Methodology

3.1 Introduction

This research aimed to build a substantive theory to explain what it means to be a person with albinism (PWA) in Nigeria with respect to social wellbeing. In simple terms, a substantive theory is the theoretical interpretation and explanation of a phenomenon that has been studied within a specific context (Birks & Mills, 2015). The methodological approach that was considered most appropriate for this study is embedded in the fundamentals of constructivist grounded theory (CGT) which are characterised with inductive processes and mutually constructed interpretation between researcher and research participants. CGT for this study was inspired by my theoretical standpoint in that the realities of social inequities, social inequalities, and social injustices will have significant adverse effects on people's health and social wellbeing outcomes. Ontologically, I also acknowledge that there is no singular truth to experiencing social realities. Given that experiences are contextualised within certain historical, social and situational conditions, realities are able to manifest relatively and thus, hold different meanings to individuals who have had or are having similar experiences. Complementing this ontological stance is the epistemological assumption that understanding and interpreting the realities of inequalities and injustices and causative social processes can be constructed through personal experiences and perspectives based on different socio-cultural backgrounds and life exposures.

3.2 Methodology

Grounded theory as a methodology for qualitative research has three major variants (Khan, 2014). The first variant championed by Glaser and Strauss (1967) positions the researcher as an objective and neutral-minded moderator of data. Glaser's (2002) objectivist stance

considers data as a matter of discovery and as such aligns with the positivist paradigm of an external reality that exists independently of social influences (Annells, 1996).

The second variant of grounded theory propounded by Strauss (Strauss, 1987; Strauss & Corbin, 1990) and later revised by Juliet Corbin (Corbin and Strauss, 2008) takes a perceptual shift from Glaser's approach to data analysis. According to Glaser (1992), the emergence of a theory is enabled through an inductive approach to data analysis. In contrast, Strauss (1987) favoured a deductive approach to the analysis of data and presented grounded theory as a method for verification. Strauss' work with Corbin (Strauss & Corbin, 1990, 1998) offers structured systematic procedures to qualitative data analysis that recognises participants' voices and also attempts to locate social realities within the relative context of the social environment.

The third variant of grounded theory posited by Charmaz (2003, 2006, 2014) adopts a constructivist approach to data collection and analysis. Her perspective agrees with Strauss and Corbin (1990, 1998) on the account of contextualising social realities relatively within the social environment. However, Charmaz (2014) does not consider grounded theory as a method of verification because there is no single universal truth about the realities of social experiences. Nevertheless, she maintains that the product of a grounded theory has to be validated through data, a perspective that is inspired by Glaser's (1992) inductive approach to data analysis. However, unlike Glaser's (1978, 1992) stance that data is simply discovered, Charmaz's method of conducting grounded theory prides itself in considering participants as active partners in the research process, and thus, she posits that data is both constructed and interpreted as a joint venture between researcher and participants while at the same time allowing them to declare their individual subjectivities based on social influences. Given this background, the choice to adopt constructivist grounded theory as the most appropriate

methodology to answer the research questions are based on (i) its stance on the acknowledgment and use of extant literature, and (ii) its subjectivity of data construction and interpretation to the voices of participants.

3.2.1 Acknowledgment and use of extant literature

Classic grounded theory (GT) as pioneered by Glaser and Strauss (1967) advocated that researchers should rid themselves of preconceived ideas and maintain objectivity in exploring a phenomenon. The notion of objectivity in GT has been questioned by several qualitative researchers who have argued that it is impossible for a researcher to embark on a study without any agenda, foundational knowledge or ideas about the study area (Allan, 2003; Holton, 2009). However, Glaser (1978) stressed that while the implied argument holds some validity, preconceived ideas should only earn its way into data analysis and not for the data to be treated based on preconceptions. In this view, Glaser (1978) argued that the early use of literature would contaminate the authenticity of data collection and analysis.

In an attempt to emphasise the importance of objectivity, classic grounded theory advocated the delay of conducting a literature review until data analysis is completed. Glaser and Strauss (1967) and later Glaser (1978) considered this standpoint as a way to avoid examining collected data through the lens of prior ideas, otherwise known as “received theory” (Charmaz, 2006, p.165). Initially, this principle presented me with some philosophical confusion being a grounded theory novice. I had to contend with finding a justifiable way to conduct this study without subjecting myself to evidence-based assertions and opinions on the phenomenon of albinism. However, it occurred to me that I could not assume objectivity to conduct this study given my ontological assumptions about social inequities and injustices being subjective derivatives of societal configuration. Similarly, this standpoint is also complemented by my epistemological assumptions on how to acquire

knowledge on the realities of social injustices with respect to the life experiences of PWA in Nigeria. What this means is that the entirety of the experiences of PWA in the Nigerian society is in itself a subjective phenomenon. Furthermore, gauging different arguments to validate or refute the delay of conducting a literature review enabled me to realise that any methodology that demands objectivity was inappropriate to answer the research questions.

On one hand, while I understood that delaying the literature review emboldens me to articulate my data-driven ideas in the study appropriately, I realised that I am however not unexpected to *“bring to the inquiry a considerable background in professional and disciplinary literature”* as stated by Straus and Corbin (1990, p.48). Recognisably, the early use of literature signalled the dichotomy of methodological speciality between Glaser and Strauss. Straussian grounded theory (Strauss & Corbin, 1990) recommends literature review and procedural guidelines for data analysis as a way to achieve induction, deduction, verification, and validation all of which were regarded as “absolutely essential” to theory development (Strauss, 1987, p.12). Glaser (1992) viewed this as a betrayal of the fundamental precepts of classic grounded theory; he argued that theory should ‘emerge’ and not ‘forced’ as Strauss’ version is seemingly likely to promote.

On another hand, I was confounded by Glaser’s seemingly ambiguous standpoint when he stated that:

“there is a need not to review any of the literature in the substantive area under study” (Glaser, 1992, p. 31)

Whereas, in his 1978 *Theoretical Sensitivity* he had stated that:

“It is necessary for the grounded theorist to know many theoretical codes in order to be sensitive to rendering explicitly the subtleties of the relationship in his data” (Glaser, 1978, p.72).

The quote above interpreted to me as an antithesis of Glaser’s perspective that the grounded theory researcher should approach the study *tabula rasa*⁴.

In partial agreement with Glaser (1978, 1998), Charmaz (2006) acknowledges that there is a risk of forcing the processes of data collection and analysis into concepts of personal agenda that may have been influenced by incautious use of literature. However, she recognises that data collection and analysis are "created from shared experiences and relationships with participants and other sources of data" (Charmaz, 2014, p.239); other sources of data to include extant literature. According to Charmaz, literature should not be ignored but should be used to gain a preliminary understanding of the social processes that characterise the phenomenon (Bryant & Charmaz, 2007). Nevertheless, she warns that preconceived theoretical concepts obtained from literature may only serve as a road map to examine data and not to offer automatic codes for data collection and analysis (Charmaz, 2006). In consonance, Schutz (1967) warned against ‘common sense theorizing’ which happens when the researcher’s personal views and experiences are forced into the data collection process. While the argument on the use and timing of literature review for grounded theory studies may be ongoing, Charmaz believes that a researcher brings to the research a considerable influence of his/her social identity, beliefs, and experiences that may already be reflected in

⁴ *Tabula rasa* is a Latin phrase. In the context of this study, it means ‘[with a] blank state of mind’

literature. Nevertheless, the risks of contaminating the grounded theory process can be significantly minimised when the researcher is reflexive by subjecting him/herself to as much scrutiny and critical appraisal as applied to the research process (Charmaz, 2006; Corbin & Strauss, 2008; Liamputton, 2009). Granted, the remarkable feature of CGT affords me the liberty to acknowledge my subjectivities throughout this thesis.

Admittedly, my preliminary awareness of this topic area is grounded in the social construction of albinism and PWA as disseminated in media and scholarly literature. Growing up in Nigeria, my childhood was influenced by societal values of trado-cultural and religio-cultural beliefs. In Nigeria, any occurrence out of the ordinary was considered spiritual and so is albinism and PWA. Even though I did not quite understand why this group of people appeared differently, I was always fascinated by the rapid movement of their eyes (nystagmus) and their high perception of vision at night-time. I had a classmate with albinism in secondary school whom the class always teased; during day-time, he would withdraw himself from social gatherings in the dormitory. However, at night time, he was known to sneak up at anyone who had teased him during the day and scare them as retribution for how they had treated him earlier in the day. This behaviour gave him a formidable persona, and I dreaded crossing his path regardless of the time of day. I had this fearful impression of PWA until I got to the university. In my second and third years as an undergraduate, I was paired with another male student with albinism for biology laboratory practical classes. At first, my impression of PWA prevented me from fully engaging with him, but as time went by, I realised he was harmless and would even laugh at jokes made at his expense. He was not from a wealthy family, but he lived quite decently within his means. Even though he had nystagmus, he was very hardworking and amiable. We became friends, and he helped me to attain a better understanding of albinism and the daily struggle to fit in and thrive. My

engagement with him made me realise that he was in every way human as everybody else except his poor eyesight and low tolerance for sunshine. This experience enabled me to rid myself of all mistaken impressions, and I became more open-minded about PWA.

Furthermore, I was able to reposition the subjectivities that once formed my perception about PWA. This consciousness enabled me to conduct this study without shame or fear of associating with PWA. In essence, I was able to engage with participants without prejudice or devaluation of their humanity based on physical appearance and more importantly, without the desire to impose on them the preconceived social construction of albinism.

Following Charmaz's (2005, 2006, 2014) approach to the cautious use of literature enabled me to understand and evaluate the methodologies that have been adopted in this topic area so as to avoid repetition of conceptual and methodological mistakes and oversights (Dune, 2011). Furthermore, I recognised that engaging with literature from the on-set honed my sensitivity to subtle variations in data and helped me gain clarity on how to get the best outcomes when interviewing study participants.

In summary, the cautious using of extant literature enabled me to acknowledge the evidence therein, while at the same time, I retained a consciousness of multiple realities that may exist outside the scope of literature (Charmaz, 2008). What this means for this study is that while data is the principal determinant of the emerging theory, the emerged theory was used to determine the scope of the literature review (as already stated in Chapter 2 Overview).

3.2.2 Co-construction of ‘meaning’ with the participants

This research study aimed to develop a theory on what it means to be PWA in Nigeria by using the most plausible and simplest theoretical explanations, otherwise known as “abductive inference” (Charmaz, 2006, p.103) to make sense of participants’ biographies. Therefore, it would be unjustifiable to isolate the interpretations and explanations rendered to data from the contextual factors of time, place, culture and circumstances that shaped the shared views of the study participants – this is also one of the rationales for adopting constructivist grounded theory.

I have had to make a decisive transition from classic grounded theory of Glaser and Strauss (1967) to constructivist grounded theory (CGT) of Kathy Charmaz (2000, 2006, 2014) whose philosophy hinges on the mutual generation and transmission of meaning between participant and researcher and particular respect and cognisance to the participant’s voice. This is because the data required to answer the research questions and authenticate the findings in this study can only be obtained from the individuals who have had first-hand experiences of being a PWA.

Charmaz’s CGT is a derivative of the social constructivism theory propounded by Berger and Lukmann (1966) which proposes that knowledge is constructed through progressive internalisations of actions and interactions with others. The theory of social constructivism emphasises the cooperative and mutual creation of knowledge between people of similar experiences and interest. Constructivism as an epistemology places focus on an individual’s [the researcher] participation in socio-culturally influenced practices and face-to-face interactions with participants (McKinley, 2015). In other words, true understanding and interpretation of experience are socially constructed, and knowledge is not independent of social interactions. The ultimate goal of constructivism is to constitute social and cultural

experiences by actively interpreting individuals. In essence, the interpretations derived from people's experiences as determined by their culture, society or historical context cannot be credibly achieved without their contribution (Crotty, 2010).

Having established mutually constructed interpretation as the outcome of social constructivism, the theoretical perspective of interpretivism became applicable.

Interpretivism stems from the idiographic nature of social sciences which places focus on explaining human experiences. According to Weber (1970), interpretative sociology considers the individual and his action as the basic unit, as its "atom" (p. 55). In this approach, the individual is the upper determinant and also the primary driver of meaning, thus implying that the participant provides the foundation upon which the researcher builds a grounded interpretation. The active role of the research participant(s) as an interpretivist actor remains central to the constructivist stance of Charmaz (2004) in that the participant provides the foundation upon which the researcher builds and validates an inductive interpretation. Therefore, the meaning and explanation of a phenomenon are mutually constructed by the participant and the researcher.

In addition, the elements of symbolic interactionism as a language and communication tool in giving meaningful construction and interpretations of experiences became relevant to the co-construction of data (Charmaz, 2008). This fact agrees with Psathas (1973) who states that:

"The implication of the symbolic interactionist perspective is that the actor's view of actions, objects, and society has to be studied seriously. The situation must be seen as the actor sees it, the meanings of objects must be determined in terms of the actor's meanings and the organization of events must be understood as the actor organizes it" (Psathas, 1973, p.6-7).

In this light, Charmaz (2009) advocates that researchers should attain an insider perspective by “getting inside the experience and taking it apart” (p.142). By so doing, the construction of meaning (of feelings, perceptions, and experiences) is viewed through the lenses of the participant through privileged dialogue and entry into the participant’s milieu.

Lincoln and Guba (1985, p.304) identified ‘prolonged engagement’ as one of many strategies one may adopt to bring credibility and trustworthiness to a qualitative research study.

‘Prolonged engagement’ in this regard can be otherwise regarded as “the development of an early familiarity with the culture of participating organisations” (Shenton, 2004, p.65) which corresponds with insider perspective. In other words, credibility in grounded theory may be considered as a derivative of constructivism, unlike objectivism which emphasises on generalisation and validity.

In comparison, objectivist grounded theory as championed by Glaser and Strauss (1967) and progressively advanced by Glaser (1978) does not acknowledge the voice and role of the participant in theory development. To the objectivist grounded theorist, data exists in an external reality waiting to be discovered and deciphered by an objective observer. While objectivist grounded theorists may yet adopt observational methods for data collection, they place themselves far removed from the research participants and the social environment that constitutes their realities. Congruently, Glaser’s (2002) disquisition in his effort to debate the authenticity of Charmaz’s constructivist grounded theory states that:

“The product, a GT, will be an abstraction from time, place and people that frees the researcher from the tyranny of normal distortion by humans trying to get an accurate description to solve the worrisome accuracy problem” (Glaser, 2002, vol.3, p.1).

In the above stated, Glaser’s sense of distance from the participant became apparent when he regarded grounded theory as an ‘abstraction’ rather than an ‘interpretation’ that absolves the research from the distortion [contribution] of humans [research participants]. His use of the noun ‘*tyranny*’ may be interpreted to mean that he considers the contribution of research participants as dictatorial, therefore, undesirable. Furthermore, given that abstraction is the conceptual representation of ideas without concrete evidence (Chazel, 2006), it sufficed to speculate that classic objectivist grounded theory only advocates for what the researcher holds valid about his study, thereby, making him the sole determinant of the emerging theory.

Another factor that made CGT more preferable to classic objectivist grounded theory for this study stems from Glaser’s assertion that:

“Much GT [grounded theory] interviewing is a very passive listening...It is hard for mutually constructed interpretations to characterize this data even though the data may be interpretive...” (Glaser, 2002, vol.3, p.2)

Again, by stating that grounded theory interviews are conducted by passively listening to the interviewee, Glaser (2002) appears to be saying that a researcher chooses to hear what he wants to hear from the participant and that the participant’s voice is irrelevant; hence, it is unachievable for data to be mutually constructed.

Communication behaviourist Larry Barker (1971) defined passive listening as “*barely more than hearing*” and active listening as “*involved listening with a purpose*” (p. 9-13). I endeavoured to understand why Glaser would opine that grounded theory researchers passively listen to their study participants – a probable pretext that occurred to me was attributed to Glaser and Strauss’ (1965) “Awareness of Dying” which was an observatory exploration of how professionals and their terminal patients coped with the news of impending demise. It occurred to me that the sickly state of health of the patients might not have permitted much interactive communication during data collection; hence, the need to recommend passive listening as a method for data collection in grounded theory.

In what appears to be a vague compromise of his standpoint, Glaser (2002) seemed to make an allowance for the recognition of the participant’s voice and influence on the interpretation of data.

“If this is the way the data come down, then fine... It just remains to be clear about the data that obtains and that is whatever it is. When I say that some data is interpreted, I mean the participant not only tells what is going on, but tells the researcher how to view it correctly—his/her way” (Glaser, 2002, vol.3, p.2)

In the above extract, Glaser can be heard implying that mutual interpretation of data can be achieved by giving the participant such latitude as to how he/she wants his/her shared data to be understood.

Mutually generated knowledge and co-construction of meaning between researcher and participant(s) remains a defining principle of constructivist grounded theory. In disagreement with objectivist grounded theory, Kathy Charmaz posits that “like wondrous gifts waiting to

be opened, early grounded theory tests imply that categories and concepts inherent within the data, awaiting the researcher's discovery... not so" (Charmaz, 2002, p.522).

Constructivist Grounded Theory in practice, remains a relatable methodology considering that it advocates for the immersion of the researcher into the participants' lived realities in such a way as to evoke the sensitivities necessary for understanding and interpretation of data. Constructivism as an offshoot of the interpretive paradigm assumes that knowledge about social processes and interactions cannot be comprehended and interpreted from outside the milieu of the understudied and acknowledges the complementary creation of said knowledge by the viewer and the viewed (Charmaz, 2000). In a later publication, Charmaz reiterated that "through our methods, we first aim to see this world as our research participants do – from the inside" (Charmaz, 2006, p.14).

The above aphorism of 'insider perspective' holds much relevance to my study of albinism in Nigeria because sharing similar national origins with participants affords me a certain depth of insight into the social constructions of albinism. However, I must state that it is through the in-depth narrative conversations about their experiences that I am only able to claim to have obtained an insider perspective.

Unlike objectivist ground theory, constructivism can neither be achieved by distance from participants nor passive listening. Charmaz and Mitchell (1996) brought this to bear by recommending that 'a keen eye, open mind, discerning ear, and a steady hand can bring you close to what you study'. In essence, constructivist grounded theory interviews are structured to be informal and conversational so as to create an equilibrium of power between the researcher and the participant(s) in such a way as to acquire rich data.

My adoption of constructivist grounded theory implies that the emerged theory in this study can be considered a credible representation of the meaning of being a PWA in Nigeria only if the data is examined and interpreted through the same philosophical lens as I have done.

3.3 Constructivist Grounded Theory (CGT) over other qualitative methodologies

The first application to the Faculty of Health and Social Care ethics committee was returned with some suggestions, one of which was for me to consider adopting phenomenology since my study would explore life experiences. My reply to the suggestion was that I adopted [constructivist] grounded theory because it would enable me to give an in-depth conceptual explanation of the process underlying the phenomenon rather than to provide a descriptive understanding of lived experiences as is relatable to a phenomenological approach.

While phenomenology remains a valid methodology that may be used to develop rich descriptions and ‘pathic’ understanding of an experience (Van Manen, 2007), it has been criticised for being myopic in that the approach has little or no interest in conceptualising the experience (Braud & Anderson, 1998). Hence, a phenomenological approach may overlook the situational and social factors that contributed to that experience and its resultant outcomes. CGT suited the inquiry of this study in ways more than one. Firstly, a phenomenological perspective is not designed to develop theory and therefore made it inapt for this study (Cohen, 2000). Secondly, adopting CGT enabled me to establish thematic relationships between the experiences of the study participants and this was made possible by the use of the constant comparison method as advocated by grounded theory pioneers Glaser and Strauss (1967). Lastly, given that a phenomenon is likely to have multiple realities, Kathy Charmaz’s (2008) CGT allowed me to examine and explore the different facets of experiences as lived and narrated by the participants.

A reader of this thesis might argue that there are ethnographic elements to this study. Nevertheless, my preference for CGT over ethnography is rooted in the words of Charmaz as she notes that “[some] ethnographers become immersed in worlds that bear little resemblance to those from which they came. Even if they believe that they think, act, and feel like members of their studied world, one sharp difference remains: ethnographers know they can leave” (Charmaz, 2006, p. 24). Here, it appears that Charmaz regards the ethnographer as an outsider with no strings of identity with the studied world. In the case of this study however, CGT allows me to bring my familiarity with albinism into this research journey. Even though I do not have albinism and will never know what it means to be different as a PWA, but by being Nigerian, I am not removed from the fact that I share a responsibility for how albinism is socially constructed and how PWA are perceived given my own experiences as presented in Section 3.2.1 and Chapter 8.

Charmaz (2014) argues that while ethnographers frequently adopt a grounded theory approach to making sense of data, ethnography is characteristically embodied in observing and presenting the phenomenon at a descriptive level without paying considerable attention to the multiplicity of processes and actions. This identified feature made ethnography a less suitable methodology for this study on two bases. Firstly, given that Nigeria is a country with over two hundred tribal ethnic groups across three major tribes, I was aware that tribal variations may have underlying influences on the meanings of life experiences for PWA. Thus, it would not be scientifically sound to address this topic through the lens of a unitary cultural society that ethnography would have offered. Secondly, I recognised at an early stage in the research journey that processes and actions are key to making an interpretive sense to life experiences if indeed I aspire to generate a conceptual theory. Ultimately, constructivist grounded theory offered me the tools to achieve the aspirations of this study.

The collected data for this study were stories of life experiences which participants have chosen to narrate in a chronological life-course order. Correspondingly, the data were analysed and the findings were presented in the same chronological order that participants have told their stories. The decision to treat data this way is based on two reasons. Firstly, it acknowledges that ‘meaning’ was mutually constructed with participants. If it made sense to participants to tell their stories from childhood to adulthood, then the precepts of CGT require that data be treated accordingly. Secondly, treating data chronologically made it possible to identify the processes and actions that conceptualise their life experiences at different stages of life. Indeed, processes and actions are crucial to understand and explain phenomena of significant implications for wellbeing such as social injustices. Otherwise, it becomes less likely to be able to suggest evidence-grounded recommendations for the appropriate interventions.

Having stated my position on this, I recognise that looking at the data analysis and presentation of findings chapter, a reader might instinctively be inclined to consider this study as a narrative inquiry. Without misplacing the focus of this project on theory construction, the analytic approaches of narrative inquiry have been found to be inapplicable to this study in matters of foundational considerations for data, procedures to data analysis and reporting.

Due to its philosophical origins in humanities, narrative inquiry frames data in terms of a story-telling structure by attempting to identify a plot or genre to categorise the story (Daiute & Lightfoot, 2004). Usually, narrative analysis aims to fragment the plot of the story in a unilinear sequence of start-middle-end (Riesmann, 1993; Polkinghorne, 1995). In light of this, narrative analysis treats stories as if life experiences are finite. Even if this assumption of finite life experiences is true in some cases, it remains inapplicable to this study considering

that the life experiences of participants in this study are processual and ongoing in relative responses to the actions of the society.

Given that stories feature characters, narrative analysis pays more attention to the functions and actions of the story characters rather than the processes underlying their actions (Silverman, 2014). In other words, data structure and analysis become more about ‘who is doing what’ than it is about ‘the why’ for what they are doing. Thus, it seems as if a character [the storyteller] is expected to establish his/her identity without acknowledging his/her own subjectivities (Riessman, 2011). In terms of examining data, narrative analysis permits the fragmentation of transcripts by way of deleting phrases and comments that the interviewer regards as irrelevant (Emden, 1998). This procedure may be considered as a method of “restorying” which is aimed to explicate the storyline with respect to themes that delineate “time, place, plot and scene” (Creswell, 2013, p.74). This point of view is a testament to a commonly referenced structural framework for narrative analysis proposed by Labov and Waletzky (1997) that is used to *restory* narrative data in terms of (i) an abstract that summarises the entire story; (ii) an orientation that typifies the context and plot; (iii) actions of the narrator; (iv) meaning of the narrator’s actions; (v) consequences of the narrator’s actions; and (vi) a coda that concludes the narrative. As mentioned earlier, if I was to adopt a narrative analysis approach, the social processes that underlie the participants’ experiences are likely to be missed or underemphasised. The totality of my reasons for not adopting a narrative analysis approach rests on two bases. Firstly, the technique of *restorying* has the potential to undermine the narrator’s voice, thereby causing contentions on the ownership of the story (Pinnegar & Daynes, 2007). Secondly, if the narrative is to be examined this way, there is likelihood to force data into preconceived concepts and miss taken-for-granted

aspects of participants' lives thereby compromising the credibility and resonance of the emerged theory (Charmaz, 2006; 2014).

3.4 Summary

In this chapter, I have attempted to clarify and justify the reasoning behind my preference for constructivist grounded theory. Clarification and justification for the preferred methodology was presented in two ways. Firstly, by examining the features of three major variants of grounded theory methodology, and deciding that the variant that allows subjectivity in terms of extant literature and participants' contribution was the most applicable to answer the research questions. Secondly, by scrutinising the features of other qualitative research methodologies and identifying their inapplicability to answer the research questions. In sum, the philosophical and analytical tools required to develop a substantive theory in this study were those that are consistent with the methodological framework of constructivist grounded theory.

Chapter 4: Methods

4.1 Introduction

This presents the procedures adopted to manage this project with respect to the recruitment of participants and data collection. The concept of obtaining an insider perspective on a phenomenon is central to Charmaz's (2006; 2014) constructivist grounded theory (CGT) methodology. The philosophical underpinnings of CGT therefore made it imperative for me to relate with persons with albinism (PWA) in a way that would appeal to them to offer me an inside perspective of their experiences. Considering that human beings are active agents in constructing the meanings of their realities (Strauss, 1987), CGT recognises that the construction of knowledge takes place under certain conditions (Charmaz, 2014). These conditions are based on negotiating for privileged access into participants' social environment and more importantly, gaining their acceptance (Prus, 1996; Thornberg, 2010a). Dey (1999) advises that a strategic way to assume the role of an insider is by the means of continuous negotiations aimed to establish a rapport of respect, and familiarity with prospective research participants. Charmaz (2014) contends that successful negotiations would afford the researcher an opportunity of seeing the world through the perspective of the research participants "from the inside" (Charmaz 2014, p.24). The objective of gaining an insider perspective is in itself a continuous process of negotiation that engenders trust and adoption between researcher and participants (Cain, 2012; Thornberg, 2010b). Fundamentally, the characteristics that enabled me to obtain an insider perspective as I undertook this study to understand what it means to be a PWA in Nigeria were my familiarity with the socio-political climate of participants' social environment being a Nigerian myself. My show of sincere empathy for PWA and solidarity with their campaign for social equity, equality and justice played an additional role as well.

4.2 Gaining perspective as an insider

The choice of my research topic was borne out of displeasure with social inequities, inequalities and social injustices experienced by vulnerable groups. Based on this premise, I was faced with the decision of focusing on a vulnerable group within a relatable population. Charmaz (2008) highlights the significance of the researcher's relatedness and position to the construction of the lived realities of those who are being studied. For me, this implied that I should be familiar with the sociocultural background of prospective research participants. Hence, the ideology of gaining perspective as an insider became an appropriate notion to adopt if rich data was to be obtained. To a significant extent, this informed my choice to focus on PWA in Nigeria.

In plain terms, Merton (1972) identifies insiders as the members of specified groups while outsiders are non-members. Providing clarity, Griffith (1998) described the insider researcher as someone whose socio-biography shares similarities with the researched group while the outsider researcher is someone who lacks prior socio-biographical knowledge about the group under study. Going by Griffith's (1998) description, I was inclined to consider myself an insider because being a Nigerian affords me some sense of familiarity with the general sociocultural outlook on PWA in Nigeria. However, I recognised that Charmaz's constructivist grounded theory (CGT) methodology considers an insider in terms beyond shared national origins.

Insider perspective is a notion advocated by Charmaz (2006) on whose CGT methodology this study was based. In referencing her opinion on insider perspective, Charmaz (2006) states that "through our methods, we first aim to see this world as our research participants do – from the inside" (p.14).

Having stated this, I must also acknowledge that sharing a similar nationality with participants did not confer upon me a status of an *insider* in all entirety. Even though I am a Nigerian, I still bore in mind that I do not have albinism, nor do I have a history of albinism in my family which means that I could never claim full understanding of what it means to be a person with albinism. Simply put, it is not enough to claim being an insider based on a shared national identity with participants. In light of this, my assumed role as an insider was not without limitations. Therefore, it became necessary to also consider myself an outsider seeking privileged access to the participants' life experiences.

My insider-outsider status resonated with the opinions of Pike (1967) when he categorised a researcher's status as being either emic, that is, insider; or etic, that is, outsider. Pike (1967) argued that a researcher who is not investigating himself/herself starts out as an outsider and may only attain the status of an insider on the discretion of participants. McCutcheon (1999) clarifies the insider (emic) status as:

“the outsider’s attempt to produce as faithfully as possible the informants’ own descriptions while the outsider (etic) status is the observer’s subsequent attempts to take the descriptive information they have already gathered and to organize, systematize, compare that information in terms of a system of their own making”
(McCutcheon, 1999, p. 17).

Going by the above-stated, it sufficed to surmise that a researcher begins and completes the study as an outsider. His/her insider status [if granted by participants] merely functions to complement his/her outsider status. Admittedly, this notion applied to me given the context of this study. In other words, I was able to enhance my outsider perspective on albinism with the insider access that I was granted to understand how PWA in Nigeria conceptualised their

life experiences in relation to the status of their health and social wellbeing. In simple terms, as an insider, I was able to obtain a deep perspective on the realities of being a PWA in Nigeria. It is this newly acquired knowledge that enabled me to fulfil my obligation as an outsider to interpret, consolidate and disseminate the findings that have emerged from this study.

The rationale and genuineness of empathy that inspired this study was openly shared with prospective participants. Thankfully, they responded positively and this enabled my journey to gaining privileged perspective as an adopted insider. Nevertheless, it is essential to acknowledge that my gender as a male might have impacted the gender imbalance in the sample size. The reasons for this are discussed in Chapter 8 – Reflexive Account.

4.3 Participants sampling, recruitment and study settings

While there is no specified number of participants required for a grounded theory research, an average of twenty-five participants is suggestively appropriate as these are deemed to be considerably representative of any target group of research interest (Thomson, 2011).

Notwithstanding, Glaser (1998) and Stern (1994) make a case for small sample size as non-consequential to grounded theory given that grounded theory methods are directed at developing robust, inter-related conceptual categories which in other words implies a focus on the richness of data and not necessarily on the number of participants. Eleven participants were involved in this study. Albinism, being a socially sensitive phenomenon in Nigeria might be attributable to the small number of participants that were willing to share their life stories and experiences. Morse (2000) and Sobal (2001) identified the sensitivity of a research topic as a determinant factor to the sample size a researcher can attain for a study. As a grounded theory rule to gain theoretical saturation, Morse (2000) recommended that multiple interviews be conducted for participants so as to obtain rich and quality data that

would provide in-depth understanding of the phenomenon. Theoretical saturation is an integral part of an advanced form of [theoretical] sampling in grounded theory that necessitates additional collection of specific data to fully develop the properties of a theoretical category until no new insights emerge (Charmaz, 2006; Glaser, 2001). Adopting this recommendation, each of the participants in this study was interviewed as many times as necessitated by the need to gain clarity and fill in gaps to attain theoretical saturation that is sufficient ⁵to support the emerging theory. The number of times that each participant was interviewed and the means of interview are as presented in Table 3. As previously stated, multiple interviews were conducted to gain clarity on participants' stories, to confirm details in their stories so as to avoid misinterpretation, and to obtain additional information as data analysis progressed. This approach was made possible because participants had indicated their willingness to participate in additional interviews if need be.

4.3.1 Study settings

Study participants were recruited from The Albino Foundation (TAF) in Abuja, Nigeria. TAF is a non-governmental organisation advocating the recognition and respect of the rights and socio-economic inclusion of PWA in Nigeria.

On 13th October 2015, an email was sent to the founder of TAF where I detailed the rationale and purpose of my research study and sought approval to access participants from TAF membership. On 15th October 2015, a reply came from TAF management, granting me

⁵ In congruence with Morse (1995), Dey (1999) posits that while several grounded theorists claim to have attained 'theoretical saturation', there is usually no verifiable way to support the claim. Hence, Dey (1999) recommends that it is safer to claim "theoretical sufficiency" (p. 257) as a way to declare that the extent of analysed data is sufficient enough to support the emerging theory. Charmaz (2006, 2014) agrees with Dey (1999). Accordingly, the author of this thesis being a novice grounded theorist adopted Dey's (1999) stance [see section 5.6].

permission to access participants from among the service users at TAF (see Appendix B). Data collection commenced in June 2016 following approval by the Faculty of Health and Social Care Research Ethics Sub-Committee.

The TAF offices are located in Jabi District, a beautifully developed urbanised residential area in Abuja, the federal capital city of Nigeria. The area features a beautiful architectural landscape comprising green spaces, several avenues of luxuriously designed buildings and a recreational park with a lake surrounding it. The district is easily accessible to commercial motorists and the location of the office is within a few seconds walking distance from the expressway that links the area to the central business district. The TAF offices are situated in the penthouse of a commercially leased building complex. The offices are air-conditioned and the windows are tinted to reduce penetration of sun-rays given the height of the office space. In addition to the administrative offices, there are two adequately furnished rooms for general meetings and one-to-one counselling sessions. There is a certified therapist among the staff who anchors counselling sessions for members needing such services. The entire settings of TAF offices offer a serene environment designed for member's convenience, comfort and privacy. Management of TAF availed me the use of their offices to meet prospective participants and to conduct face-to-face interviews provided the interviews are scheduled on business days from Monday-Friday.

At the initial stage, this study adopted purposive sampling (Bernard, 2002; Patton, 2002) as a means to identify people who are most knowledgeable about the topic from places where they could be easily accessed. This sampling strategy was based on Glaser's (1978) guidance to:

“Go to the groups which they believe will maximize the possibilities of obtaining data and leads for more data on their question. They will also begin by talking to

the most knowledgeable people to get a line on relevancies and leads to track down more data and where and how to locate oneself for a rich supply of data”
(Glaser, 1978, p. 45).

In order to define the initial sample for this study, I set out two inclusion criteria (Charmaz, 2006): (i) an individual with albinism resident in Nigeria regardless of gender, ethnicity, social status, religion and educational background (ii) the individual must be a Nigerian adult aged 18 years and above. These inclusion criteria were set to ensure that prospective participants are individuals who have first-hand knowledge and experience of the realities of albinism, as well as the maturity to articulate and communicate their responses and are able to manage their emotions during interviews.

The initial purposive sample of three PWA was used to establish sampling criteria. I met these individuals on my first visit to the offices of TAF on 3rd June, 2016. On that day, there was a group of five PWA who had visited TAF [it was while I was waiting in the reception to be called in by the Founder of TAF that I overheard them talking about coming for sunscreen lotion. TAF had through a funding partner purchased a batch of sunscreen lotion and had invited members to come for free collection]. After my meeting with the Founder of TAF, he directed me to another staff member whom I later found out to be the registered counsellor. After discussing my research intentions with her, she introduced me to other staff members and the PWA. She announced to them that I would be frequenting the offices to meet with interested members for interviews. Shortly afterwards, I re-introduced myself to the PWA that were present, explained the research to them and invited them to register their interest if they are willing to share their stories with me. Three of them indicated their interest; they gave me their names and phone numbers and we agreed that I would telephone them to schedule the interview(s). Incidentally, all members meet together as a group on the last

Saturday of every month in the offices of TAF. There were still about three weeks before the next meeting for me to meet with the larger group of members.

Following contact with the initial sample of three PWA, I adopted the snowballing technique (Biernacki, 1986) at which point I encouraged the initial sample to refer to me other people who are eligible for inclusion and might be willing to share their experiences with me, even if they are not registered members of TAF. Two other PWA were referred to me through snowballing, but neither of them attended our scheduled interviews even though the location of the interview was of their choosing. Several phone calls to each of these two prospective participants was futile.

Drawing on Blumer's (1969) advice to respect research participants and build trust and rapport (Murray, 2003; Dickson-Swift, James, Kippen & Liamputtong, 2007), all of which are essential factors to consider when conducting research with vulnerable groups (Liamputtong, 2007; Karnieli-Miller, Strier & Pessach, 2009), I started by attending monthly members' meetings at TAF office. The first meeting enabled me to introduce the study to a larger group of members and offer them the choice to participate voluntarily and withdraw without consequence or explanation. The participant information sheet [PIS] was shared with each of them to peruse while a register was opened at the reception for prospective participants to register their interest to participate without coercion or urgency. In consideration of their visual impairment, the PIS was typed in Times New Roman font size 16 and double spaced. In the case of prospective participants with limited English Language proficiency, the content of the PIS was read out to them for understanding and consent. The members were also encouraged to advertise the study to other members of the TAF community who were not in attendance at the first meeting. All this was done to afford the members an equal chance to participate.

At the end of the first monthly meeting in June 2016, three members registered their interest and interviews were scheduled to hold at the TAF meeting room at agreeably convenient time and dates. At the end of the monthly meeting in July 2016, five additional service users volunteered to participate and interviews were scheduled according to their individual availability. During the monthly meeting in August 2016, five additional volunteers registered to participate, however, only three of them attended our scheduled interviews. At the end of my four-month field visit to Nigeria for data collection between June 2016 – September 2016, a total of eleven PWA had participated through the means of voluntary interest and referrals. The data that were collected enabled me to identify preliminary categories and emerging themes.

4.3.2 Theoretical sampling

Bearing in mind the words of Charmaz (2014) that “initial sampling in grounded theory gets you started; theoretical sampling guides where you go” (p.197), I sought to seek pertinent data to enable me to gain deeper insight into the processes that contributed to the emerging categories. For example, the categories of ‘Being in a tug of war’ and ‘Disadvantaging schooling system’ (see Section 5.3.1 and 5.3.2). It occurred to me that I did not have robust data to support some of the abductive interpretations that I was rendering to these categories during data analysis. I had to contact four participants on the 21st and 22nd of April, 2019 by telephone to obtain more data that would improve my understanding of some of the properties of these categories. The process of re-visiting participants to ask focused questions that seek to explore taken-for-granted aspects of participants’ lives is known as theoretical sampling (Charmaz, 2006; 2014). The purpose of theoretical sampling is to collect specific data to develop and refine categories that would constitute the emerging theory. This type of sampling ensures that all unresolved questions are answered and gaps in data interrogation

are filled to a justifiable extent, thereby improving the conceptual and theoretical sufficiency of the analysis. Indeed, the methodological strategy of conducting theoretical sampling differentiates grounded theory from other forms of qualitative methodologies (Charmaz, 2014).

An advantage of theoretical sampling is that it enables abductive reasoning. Abductive reasoning is the freedom of using imaginative inferences to proffer the most plausible theoretical explanation to a confounding finding and re-examining data to locate where it fits (Henwood & Pidgeon, 2003; Reichertz, 2007; Richardson & Kramer, 2006). Viewing the logic of abductive reasoning in this way, a point to note is that Charmaz (2006, 2014) argues that this may account for the reason Strauss (1987) considers grounded theory as a method of verification. As far as Charmaz is concerned, CGT is not a process of verification. However, she maintains that plausible inferences and conjectures are required to be examined with empirical data.

4.4 Data collection

Primarily, data for this study was collected through one-to-one interviews. Subsequent fact-finding attempts were conducted through telephone conversations. This method reflected Charmaz's (2006, 2008) epistemology of co-construction of data and transmission of meaning between the researcher and participant(s). The interviews were semi-structured in that my opening question was open-ended which allowed the participants freedom and flexibility of thoughts and expression (DiCicco-Bloom & Crabtree, 2006). Participants' narratives afforded me the opportunity to probe and explore incidents of their life experiences that are pertinent to the research questions (Hutchinson, Wilson & Wilson, 1994; Barriball & While, 1994). I adopted Wengraf's (2001, 2004) biographical narrative interpretive method (BNIM) to manage the conversational interview sessions.

As recommended by Wengraf (2004), at the initial narrative session of the interview, I asked a “Single Question aimed at Inducing Narrative” (SQUIN) (p. 4) of ‘Please tell me the story of your life’. While the participants narrated their biographies, I endeavoured to maintain a body language to portray interest and empathy. I remained silent, maintained eye contact in a reassuring way and actively listened while at the same time took brief notes. These notes, aptly referred to as Situation-Happening-Event-Incident-Occurrence-Time (SHEIOT) (Wengraf, 2001, p.134) were on incidents I considered relevant to the research. I used keywords as the participants had narrated in order to maintain the same sense of meaning when I referred to them for clarification.

Following the initial biographical narration, I began to ask participants to clarify and explore particular incidents based on the SHEIOT notes I had taken during the life story discourse. This part of the interview was interactive, and I noticed that participants were more at ease and expressive as they recalled those incidents.

In order to bring me closer to the experience of qualitative data collection, being a novice researcher, I started by interviewing three participants as stated earlier. The interviews, although separately conducted, were more of an informal casual conversation rather than a conventional interview. I adopted this technique primarily because I was a novice researcher and doubtful about my interviewing skills. Secondly, I was eager to apply Charmaz’s (2006, 2014) recommendation for developing sensitising concepts. Data obtained from these preliminary interviews drew my attention to how these individuals situated themselves within the context of their family structure during childhood. It made me realise that experiences within the family in childhood held significant implications for their life course. This realisation helped me to use childhood experiences as a torch to illuminate the realities of life experiences for PWA during subsequent interviews.

In adherence to the iterative process of qualitative data analyses, subsequent fact-finding sessions were conducted over the telephone following written transcription of the interviews. Whilst some qualitative researchers have recommended that transcripts be shared with interviewees for accuracy of representation (Grundy, Pollon & McGinn, 2003); etiquette and validation (Kvale, 1996; Page, Samson & Crocket, 2000) and interviewee consent and approval (Saldana, 1998), I realised that this might burden the study participants unnecessarily given their visual impairment. However, to uphold the ethics of decency, equality, and joint-ownership of data, I offered to share the interview recordings if they wished to have a copy (Inter-Agency Secretariat on Research Ethics, 2005). None of the participants indicated any interest in having the tapes.

4.4.1 Ethical considerations

This study complied to the ethical guidelines for conducting research as specified in the University of Chester Research Governance Handbook (University of Chester, 2019).

Recognisably, these guidelines espouse the principles of ethical best practice as embodied in the work of Beauchamp and Childress (2013), and by the Helsinki Declaration (World Medical Association, 2013) aimed to ensure that researchers protect the safety, dignity, rights and wellbeing of research participants.

Appendix 4 Section B in the handbook stipulates that research projects outside England involving human participants but not for clinical trials must initially secure approval from the appropriate University Research Ethics Committee, after which similar approval must be sought from other relevant gatekeepers (see Appendices A and B). The four major principles of ethics that were demonstrated in this study are: (i) autonomy; (ii) beneficence; (iii) nonmaleficence; and (iv) justice (Beauchamp & Childress, 2013). In addition to these, other

ethical requirements included valuing diversity among participants; honesty and openness; accountability; personal and scientific integrity, as well as providing supportive management.

The eligibility criterion for respondent participation adhered to the principles of valuing diversity such that the eligible demography allowed the participation of all adults with albinism irrespective of gender, ethnicity, religion and social status.

The requirements for autonomy necessitated the protection of participants' confidentiality and the enablement of self-determination. To this end, all participants were given the participant information sheet (PIS). For participants with limited knowledge of English Language, I explained the details of the PIS in colloquial pidgin which is a rustic form of the English Language generally used across the Nigerian population. Participants were reminded of their prerogative to choose a pseudonym for anonymity, and I explained to them that the interview would be audio-recorded for transcription and analyses. Nine participants chose pseudonyms, while two participants decided to retain their real names⁶. Participants were made aware that they could interrupt the interview session, reschedule or terminate participation without any consequence.

According to Beauchamp and Childress (2013), beneficence encompasses doing good for others by "preventing harm, removing harm, and promoting good" (p.152). In the context of this study, this was interpreted as an obligation to ensure and protect participants' safety whilst ensuring that their participation [in however form they choose] would be to their utmost benefit. In light of this, all face-to-face interviews were scheduled to fit in with

⁶ During the last phase of revising this thesis, I contacted these two participants and explained the importance of protecting their identities for safety reasons in light of the sensitive nature of data they have contributed to the study in terms of negative relationship experiences. Afterwards, they gave me permission to replace their real names with pseudonyms

participants' convenience with respect to day and time. Thankfully, all of them choose to meet with me in the mornings before the sun reached its peak. This was particularly beneficial to them given the need for them to avoid exposure to sunshine. It meant that they could attend the interviews without any risk of harm to their skin. In addition, all face-to-face interviews were conducted in the offices of TAF because this was a familiar environment where they frequently visit, and thus, was a safe environment to meet with them. An additional advantage to conducting the interviews in an agreeably safe location such as in the offices of TAF is the assurance of supportive management given the availability of an on-site counsellor if participants become too distressed during the interviews. There were times when the interviews would end in the afternoon, at which time it would be relatively unsafe for them to move about because of the high sun. In continuing my ethical obligation of beneficence to them, I would offer to drive them to an agreeably safe spot, usually, the nearest bus stop to their houses. This way, no participant was exposed to the debilitating effect of the sunshine during the course of their participation in this study.

I was honest about the intentions and potentials of the study so that participants would manage their expectations of immediate social interventions considering that majority of them already had similar encounters with advocacy groups, and it did not seem like those previous encounters yielded any positive outcomes. In preserving my personal integrity, I always telephoned participants as previously agreed and never went late to meetings and interviews. As a way to further ensure their comfortability and wellbeing, I always had bottled water and snacks made available to participants at every interview, especially for those who brought their children to our meetings – this engendered a culture of care.

Beauchamp and Childress (2013) conceptualised nonmaleficence as “intentional avoidance of harm” (p.152). According to scholarly evidence it is not unusual for participants to become

overwhelmed with emotions when recollecting and constructing painful experiences (Elmir, Schmied, Jackson & Wilkes, 2011; Holtan, Strandbu & Eriksen, 2014). I recognised that given the discourse on albinism as presented in the literature review, it is possible that participants may express emotional responses. Thus, it was necessary for me to ensure that participants would not be at the risk of any [psychological or emotional] harm that might be attributed to our scheduled interviews. To this end, I developed a distress protocol (Dempsey, Dowling, Larkin, & Murphy, 2016) where I reminded participants that the interview room is a safe space to express their emotions. Also, it was explained to them that should they decide to interrupt the interview in the event of becoming emotionally overwhelmed, there is a TAF staff who is an on-site counsellor for support – this was aimed to minimise burnout and emotional distress (Dunkley & Whelan, 2006). The interviews commenced only after all information was satisfactorily understood, and a copy of the signed consent form returned to me.

In the context of this study, justice as an ethical and moral obligation to participants was actualised in terms of avoiding exploitation and abuse of participants, as well as ensuring that all participants were treated fairly and respectfully during the course of their participation. The majority of participants were unemployed. This meant that attending the interviews would necessitate them to spend money for transportation. In order to avoid undue financial burden, transportation vouchers were made available to all participants after every face-to-face interview. Not all the participants required or expected assistance with transportation. However, for the participants who required it, the exact value of transportation voucher for each individual was verified by the program assistant at TAF⁷ and was only handed to them

⁷ The provision of transportation assistance for service users was a usual practice at TAF to encourage attendance at monthly meetings for service users who do not have the financial resources for transportation.

at the end of the interviews. I must stress that this was not payment for their participation, nor did participants consider it as financial enticement. It was simply to ensure that participation in this study did not impoverish the participants. The vouchers were always placed in an envelope and respectfully handed over – this served to avoid embarrassment and to protect the dignity of participants. Also, participants did not incur any telephone charges because all telephone conversations with them were made from my phone during the period of physical data collection in Nigeria, and whilst I was in Chester analysing data.

Admittedly, consent goes beyond reading the PIS and signing the consent form (King, Horrocks & Brooks, 2018). Consent might as well manifest in non-verbal cues, facial expressions and body language in response to intrusive questions that might trigger feelings of discomfort and distress in participants (Charmaz, 2014). With this in mind, every line of questioning always began with “Could I ask you?” (Rosenblatt, 1995, p. 148). By this, I subliminally made it possible for participants to exercise their power to decline or disallow any seemingly intrusive line of questioning, or if I had telephoned them at an inconvenient time. I recognised that research governance is a continuous process that transcends the timeline of a study even after its completion (Judd, Smith & Kidder, 1991). For this reason, it was important for me to ensure that I continue to do right by the participants, more especially as we have become bonded to each other by a culture of adoption. Indeed, the albinism campaign has become part of who I am even as I progress my career in pursuit of equality and fairness.

A plethora of literature has posited that differences in gender, education, age or socioeconomic status may constitute interviewer-interviewee barriers to obtaining rich data (Drew, 2014; Welch, Marschan-Piekkari, Penttinen & Tahvanainen, 2002; Vähäsantanen & Saarinen, 2013). Furthermore, Bryman and Bell (2003) warns against the socially-desirability

effect whereby the interviewee only gives answers that are thought to be most preferred by the interviewer in which case the phenomenon under study would be poorly understood and misrepresented. This presumption made me conscious that my identity as a dark-skinned Nigerian man with western education and social exposure may constitute a power imbalance between the members of TAF and me such that potential interviewees may feel intimidated by my status and this may ultimately discourage productive participation. However, through my regular attendance at TAF monthly meetings and amiable self-presentation, I was able to gain familiarity and build an appreciable level of informal rapport with TAF members such that any indication of power differential was subliminally eroded. This technique gave me the confidence and assuredness that the members have accepted and adopted me as a member of their community, thereby, enabling productive and positively responsive interviews.

4.5 Summary

This chapter drew on all the methodical procedures and decisions that were taken as I engaged with participants, and by extension, with the study itself.

Table 3 below (and overleaf) shows the different demographic characteristics indicative of the socio-economic and self-narrated wellbeing status of participants. Two men and nine women participated and contributed to the study data. The gendered differences in sample size are discussed in the Reflexive Account Chapter 8.

At the time of data collection, out of all eleven participants, two were employed in white-collar jobs, two were engaged with menial and messenger jobs, while the remainder of seven participants were unemployed. Additionally, even though all participants were of marriageable age and wished to be married, only one (male) participant was married while

the remainder of the sample size was unmarried due to numerous negative relationship experiences.

Table 3: Participants' demographic information and list of interviews

Participant (Gender, Age)	Educational history	Employment status	Marital Status	Self- narrated wellbeing status	Mode of interview	Number of interviews	Composite duration	Composite number of interviews
Uma (F,39)	GCSE ordinary level	Office messenger	Single mother of two, never married	Struggles with depression, anger, and trauma from rape	Face-to-face	2	3 hours	6
					Telephone	4	30mins	
Besu (F,42)	GCSE ordinary level	Office cleaner	Single mother of two, never married	Struggles with low self- esteem, and feelings of rejection	Face-to-face	2	4 hours	5
					Telephone	3	30mins	

Cool Baby (F,28)	Did not complete secondary education	Unemployed	Unmarried, no romantic relationship	Struggles with feelings of rejection.	Face-to-face	1	1 hour 30mins	3
					Telephone	2	20mins	
Ella (F,32)	Higher National Diploma	Unemployed	Single mother of one, never married	Struggles with depression, suicide attempts, and trauma from rape	Face-to-face	1	50mins	4
					Telephone	3	40mins	
Flexzy (M,22)	GCSE ordinary level	Unemployed	Unmarried, desires a romantic relationship	Copes well with albinism	Face-to-face	1	1 hour 20mins	2
					Telephone	1	20mins	
		Unemployed			Face-to-face	1	2 hours	4

Fedizy (M,27)	GCSE ordinary level		Unmarried, no romantic relationship	Struggles with feelings of inferiority, rejection, and disappointment from failed relationships	Telephone	3	40mins	
Lina (F,30)	GCSE ordinary level	Unemployed	Unmarried, no romantic relationship	Struggles with low self- esteem, and feelings of inferiority	Face-to-face	1	1 hour 30mins	3
					Telephone	2	25mins	
Chojo (F,31)	Ordinary National Diploma	Unemployed	Unmarried, no romantic relationship	Copes well with albinism	Face-to-face	1	1 hour 10mins	3
					Telephone	2	20 mins	
Nori (F,39)	Postgraduate degree	Office assistant	Unmarried, desires a	Struggles with low self-	Face-to-face	2	2 hours 10mins	5

			romantic relationship	esteem, and lack of self-confidence	Telephone	3	50mins	
Eki (F,35)	GCSE ordinary level	Unemployed	Unmarried, no romantic relationship	Copes well with albinism	Face-to-face	2	2 hours	3
					Telephone	1	30mins	
Wales (M,35)	Physician	Private medical practice	Married, father of one	Occasional struggles with feelings of rejection, but generally copes well with albinism	Face-to-face	2	3 hours	4
					Telephone	2	1 hour	
								42

Chapter 5: Data Analysis

5.1 Introduction

This chapter presents an audit trail of the procedures and techniques adopted to transcribe, analyse and interpret data. I recognise that it may be argued that the procedures adopted for data analysis should appear in the Methods Chapter while the analytical techniques for generating the abstract interpretations should appear separately. However, I found it beneficial to weave the analysis methods with the techniques in this chapter because it made it easier for me to maintain a clear line of thoughts and make the analytical approaches transparent and comprehensible to an academic audience and lay readers alike. Thus, this chapter has been written as a descriptive interpreted theoretical narrative in a manner that aligns with Charmaz (20006; 2014) and Strauss and Corbin (1990; 1998). At this juncture, I must acknowledge that even though this study rests on Charmaz's constructivist grounded theory methodologically, the methods and techniques for analysing data were borrowed from Strauss and Corbin (1990; 1998). This is because their work provides an analytical framework that I have found easy to follow being a novice researcher. Having stated this, I must also add that Charmaz (2006; 2014) agrees with many of Strauss and Corbin's pragmatic approaches to data analysis. The reader of this thesis will also be able to identify my recurrent references to Charmaz (2006; 2014) because of the contemporary perspectives that her work contributes to Straus and Corbin's approaches to grounded theory data analysis.

Using Strauss and Corbin (1990; 1998) as an overarching road map, my approach to data analysis aims to: (a) create a rich and plausible descriptive narrative using interview transcripts, memos and researcher interpretations; (b) build a theory using advanced levels of abstract interpretation; (c) present the findings as narrated by participants. The following

sections in this chapter attempt to satisfy ‘(a)’ and ‘(b)’, while ‘(c)’ is embodied in Chapter 6 Presentation of Findings.

To begin with, grounded theory (GT) is a form of qualitative data analysis (Frieze, 2006). The fundamental features of GT analysis are (i) coding (ii) the constant comparative method (CCM); and (iii) theoretical sampling (Hood, 2007). Coding is the key process that enables the emergence of theory from data (Strauss & Corbin, 1990). In simple terms, Charmaz (2006) defines coding as the “naming of segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data (Charmaz, 2006, p. 43).

Recognisably, there are slight variations in how coding is done according to the preferences of Glaser (1978), Strauss and Corbin (1990; 1998), and Charmaz (2006; 2014). Nevertheless, ‘Initial coding’ and ‘Selective coding’ are common phases in the naming of data across all variants of GT analysis (Charmaz, 2006). However, an intermediate phase of coding is required to proceed from description to conceptual abstraction as the analysis progresses toward theoretical precision. Strauss and Corbin (1990; 1998) conceptualise this intermediate phase of coding as ‘axial coding’. In simple terms, axial coding links subcategories with categories such that the relationships between properties and dimensions of a category(s) become clear and justifiable. In short, the ultimate aim of axial coding is to organise data in terms of context for the emergence of a central category that has the potential to offer a theoretical explanation for the phenomenon. Before moving on, it is worth stating what a ‘category’ means for the benefit of lay readers. A category is a “conceptual element in a theory” (Glaser & Strauss, 1967, p.36) that represents a group of similar concepts and thus, has the potential to offer a detailed explanation of the processes identified in the data. In the same vein, ‘concepts’ are words that may be used to interpret the ideas that data seem to be suggesting (Corbin & Strauss, 2008). Charmaz (2014) acknowledges the usefulness and applicability of axial coding in identifying and integrating data around a central category,

although she does not subscribe to the approach. Instead, she contends that her approach to arbitrary link categories with subcategories as an intermediate phase in the coding process makes her analytical approach more emergent than procedural (Charmaz, 2014, p.148). Then again, Charmaz (2014) maintains that GT analysis methods are flexible as long as the analysis examines processes, centralises the study of actions and creates abstract interpretations of the data. Glaser (1978; 2005) introduces another phase of coding as ‘theoretical coding’. Theoretical coding builds on selective coding (or focused coding as Charmaz calls it) so as to move the data towards theoretical integration. In order to be able to accurately apply theoretical coding, there is the need to be familiar with a wide array of theoretical coding families many of which have been introduced by Glaser (Charmaz, 2006; 2014). Glaser (1978) contends that theoretical coding renders axial coding an unnecessary endeavour. Nevertheless, Charmaz (2014) implies that theoretical coding is at best an ambiguous approach because it remains unclear the criteria for identifying an appropriate coding family that may be applied to a study. As earlier stated, the need for clear procedural guidelines being a novice researcher made me to adopt Strauss and Corbin’s (1990; 1998). Their approach to coding follows the sequence of initial coding, axial coding, and selective coding. Strauss and Corbin (1990; 1998) offer a systematic framework that examines conditions, actions and consequences as a guide for conducting axial coding (see Section 5.4). In sum, coding as a fundamental feature of GT analysis enables the iterative processes of the CCM, which in turn drives theoretical sampling.

As recommended by Bryman (2004), Silverman (2006) and Stuckey (2014), transcription of recorded audio interviews commenced immediately after the first interview. Transcription of data for this study was conducted manually. Similarly, all subsequent stages of data analysis were conducted manually without the use of any qualitative data analysis software (QDAS). The decision not to use a QDAS is based on certain points of view. According to Glaser

(2003) and Keele and Bird (1995), a computer program not only lacks the sensitivity of a human mind but also lacks the accuracy and empathy required to recognise, qualify and infer on social processes. Similarly, Lonkila (1995) and Weitzman (2000) argue that dependence on a computer program to make sense of qualitative data potentially increases the risk of creating distance between researcher and data, thereby, risking the loss of intimacy with data. These points of view are particularly crucial to this study because of the nature of collected data. The majority of participants told their stories in pidgin English which is a colloquial form of the English Language. I feared that codifying these into a QDAS in literal translation would adulterate the depth of culturally-situated meanings contained in their stories. Nevertheless, I acknowledge that even though a QDAS does not automate the interpretive process to analysis, it is not without its advantages. Admittedly, QDAS provide a set of convenient tools to manage data and keep track of analysis, thereby, making qualitative data analysis more efficient and easily accessible (Bringer, Johnston & Brackenridge, 2006; Corbin & Strauss, 2008; Richards & Richards, 1999; Strauss & Corbin, 1998). However, given the points of view stated earlier, utilising a QDAS was not considered ideal for data analysis in the context of this study.

5.2 Constant Comparative Method

In their pioneering work on classic grounded theory, Glaser and Strauss (1967, p.105) outlined four stages of CCM: (i) comparing incidents applicable to each category; (ii) integrating categories and their properties; (iii) delimiting the theory; and (iv) writing the theory. Recognisably, all these stages are made possible through the coding processes identified in Section 5.1.

Drawing on Charmaz's (2006) definition of coding as "*naming segments of data with a label that simultaneously categorizes, summarizes, and accounts for each piece of data*" (Charmaz, 2006, p.43) offered me a clear understanding of what was required.

Charmaz (2006) provides further guidance by recommending that data should be coded in gerunds. This is because coding in gerunds help to detect actions and processes occurring in the data (Glaser, 1978). Similarly, paying attention to the language used by participants may further ground one's interpretation in data. Charmaz (2006; 2014) highlights the likelihood of participants being able to conceptualise their experiences such that they construct "innovative term(s) that captures meaning" (Charmaz 2006, p. 55; Charmaz, 2014, p. 134). These innovative terms are what she refers to as '*In vivo* codes'. It is worthy of note to acknowledge that using *in vivo* codes strengthens the co-construction of meaning as a mutual venture between researcher and participants. Equipped with this information, I proceeded to the first phase of open coding, which is the line-by-line coding.

Strauss and Corbin (1990) conceptualised open coding as the gateway to discovering what the data is about by fragmenting data into distinct parts and identifying similarities and dissimilarities across participants' stories; this process itself enables the back-and-forth comparison of data known as the CCM. According to Glaser (1978), one way to approach open coding is through line-by-line coding, which simply means naming every line of the interview transcripts. It was at this phase I began to closely examine each participant's story with the aim to tease apart the events and incidents that made up their lives up until the time of interview and started making meaning of what participants had narrated to me.

I utilised line-by-line coding in two ways. Firstly, I used line-by-line coding to compare data from the same participant as a way to examine the occurrence of repeated incidents. This was especially crucial because it helped to identify the recurrence of similar patterns in the

storyline (Charmaz, 2014; Gibbs & Taylor, 2010). Secondly, I compared the line-by-line codes I had developed across all the interview transcripts.

This is because I bore in mind that I might have worded the codes differently even though the actions and processes in that particular line of data represented similar incidents. Figure 4 below exemplifies how codes were ascribed to participants' stories in the open stage of coding:

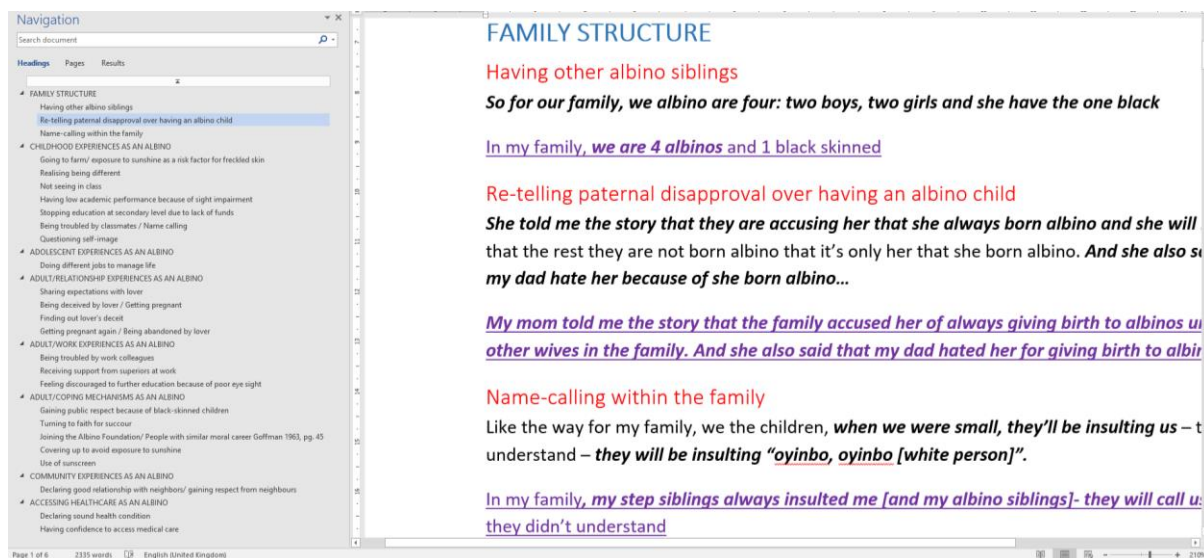


Figure 4: Screen image of line-by-line coding of data from a participant's interview transcript⁸

With this approach, I was able to refine and uniformalise the codes for ease of further analysis. It occurred to me that while some participants already made explicit statements to demonstrate the meaning they have ascribed to their experiences; some other participants were either vague in their narration or had not quite figured out what those experiences meant to them. Identifying such gaps in data helped me to refocus subsequent interviews and fact-

⁸ The 'context' of the storyline appears in blue font; the 'actions' appear in red font, while the English Language translation from pidgin form appears in purple font. The 'processes' in each line are assembled on the left hand side in the image.

finding strategies. With the use of this technique, I was able to use data comparatively to identify similarities and nuances in the life experiences of participants.

In sum, line-by-line coding sensitised my awareness to the incidents that best described participants' experiences, the processes and actions involved in these experiences, as well as the effects and consequences of these experiences on the meaning of life for the participants.

Having identified the actions and processes that led up to significant incidents in participants' life stories, the next phase of open coding I conducted was the incident-to-incident coding. Again, I approached incident-to-incident coding in two ways. Firstly, I relied on the line-by-line codes to identify similar incidents in participants' stories. Once I was able to establish similar patterns of incidents, data became more accessible to me. It was at this phase I was able to associate incidents with concepts that best conveyed what was being demonstrated in the data. Secondly, I selected incidents of similar patterns across participants' stories and made comparisons of associated concepts in order to determine the conditions that underlie those patterns. This led me on to the second stage of CCM.

The second stage of CCM entailed the integration of categories and their properties. This stage was made possible by writing memos. I considered memos as a kind of 'letter to self' because memos are personal reflections on data written in a narrative form. According to Charmaz (2006), memo-writing engages the researcher in a process of questioning one's understanding of the data which in turn stimulates a closer examination of the data. This was particularly useful to me because it was through my memos that I began to crystallise my interpretations of the data as I examined the data for context.

As an overall advantage, memo-writing enabled me to use axial coding to identify the relationships between the emerged categories (Charmaz, 2006; Glaser & Strauss, 1967; Strauss & Corbin, 1998). An example of one of the memos I wrote while examining data is presented below in Figure 5.

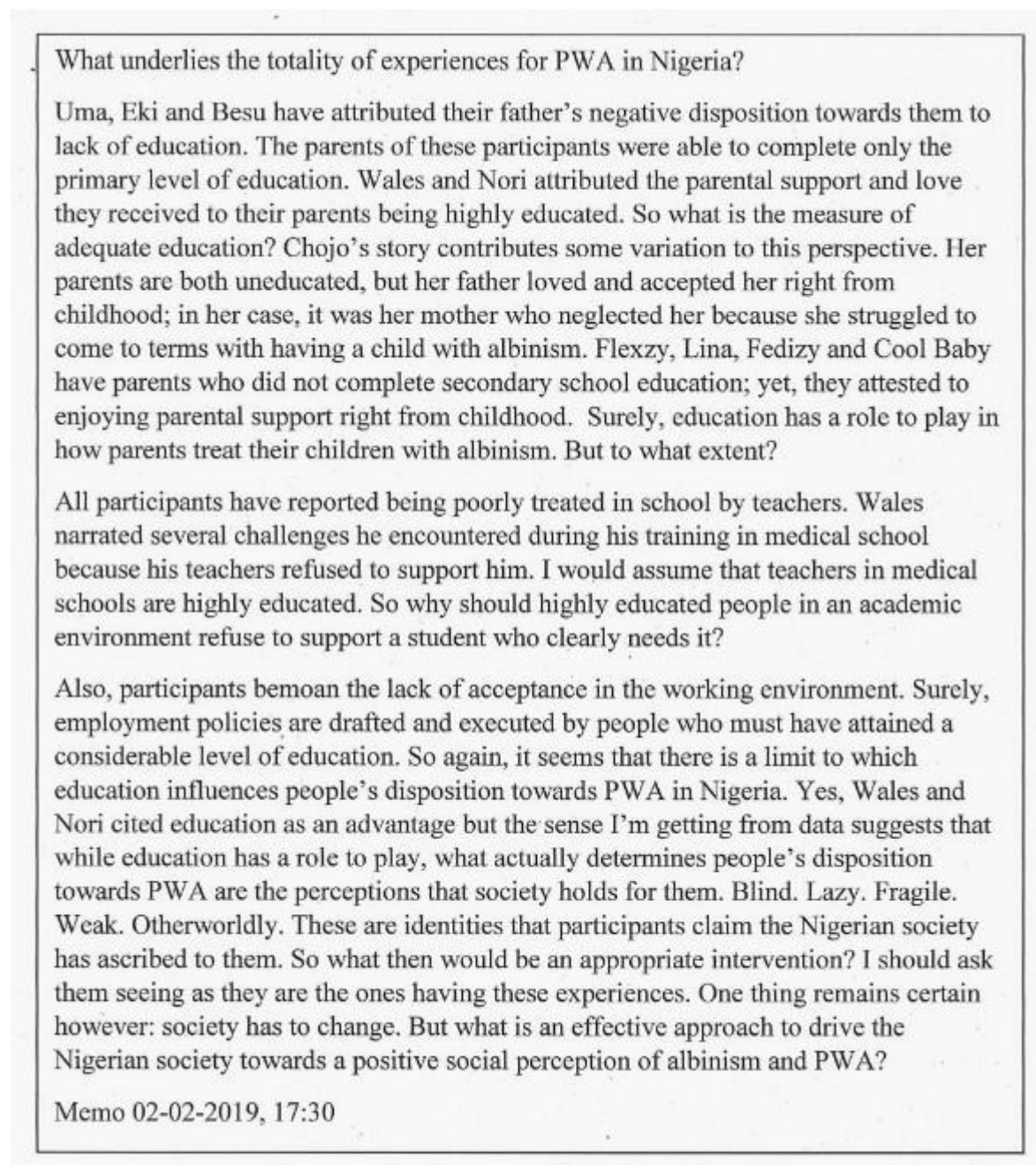


Figure 5: Memo written to document reflections on data⁹

⁹ This appears here to demonstrate memo-writing as an integral element of GT data analysis

5.3 Identifying categories

Even though examining emerging concepts had begun to provide descriptive insight to the processes that culminated into significant incidents in participants' life stories, I recognised the need to identify an abstract concept that had the analytical power to provide a graphic explanation of what data was talking about. Strauss and Corbin (1990; 1998) ideologised this abstract concept as a 'Category' which is an abstract embodiment of similar concepts and processes.

To identify and name the categories generated from the data, I drew on Strauss and Corbin's (1998) proposition recommending that categories should be defined with reference to the context and conditions within which the emerging concepts and processes occur. Figure 6 below exemplifies the transition of analysis from coding towards categorisation of experiences. Participants' stories were located in the different contexts within which their experiences occur. Within each context are certain disenabling conditions that further drive the meaning of realities for participants.

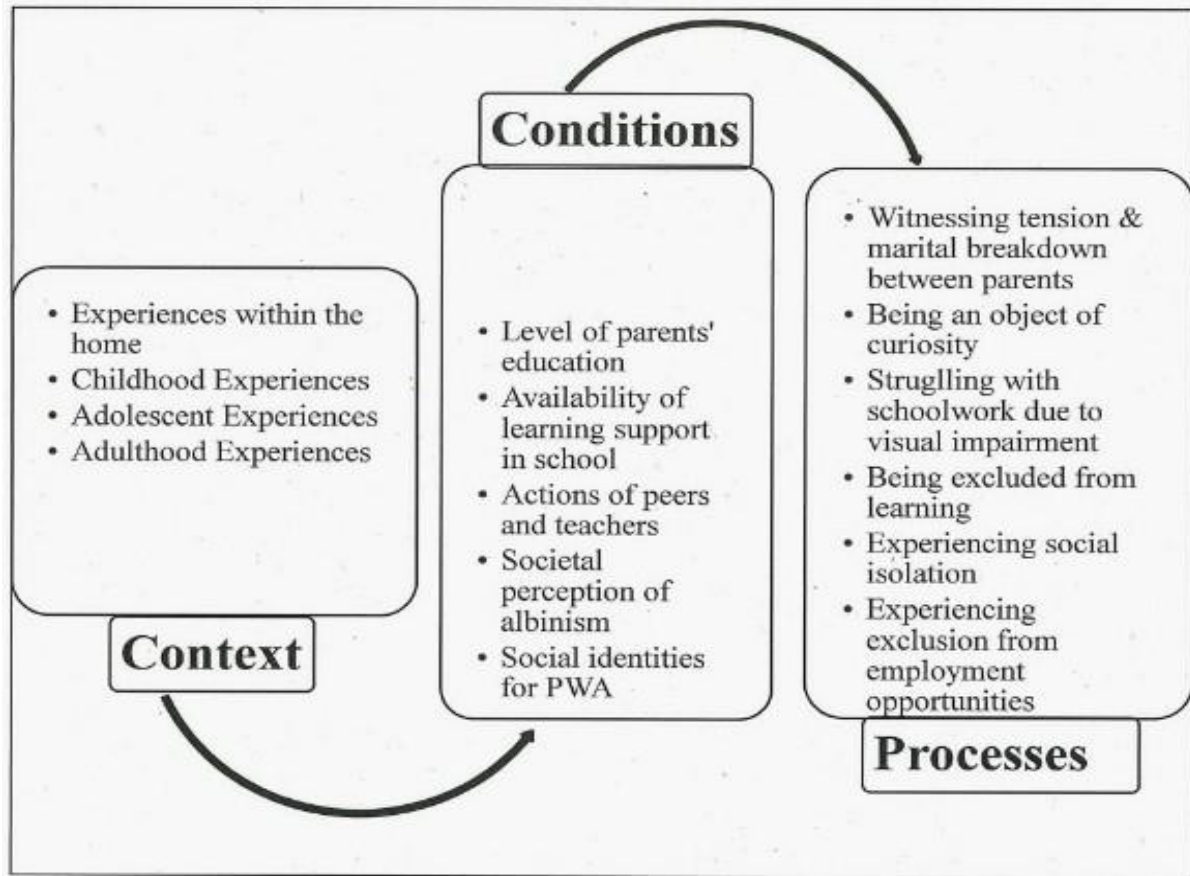


Figure 6: Illustrating the processes of disadvantaging life experiences for PWA

At the initial phase of analysis, interrogation of data from the first three participants with the use of line-by-line and incident-to-incident coding revealed that participants' commonality of life experiences was narrated around four broad contexts within which experiences of what it means to be a PWA in Nigeria can be located:

1. Experiences within the home
2. Childhood Experiences
3. Adolescent Experiences
4. Adulthood Experiences

These contexts formed the foundations for emerging conceptual categories that aimed to render a theoretical explanation of the experiences of people with albinism (PWA) and the conditions under which they occurred.

Following Charmaz's (2006) guidance to present categories and processes as "gerunds" (p. 136), categories were labelled as actions. This draws on Strauss and Corbin's (1998) inspiration in naming or labelling of the categories, whereby incidents within data, ideas and events were given names that represented what they stood for.

The interrogation of data with respect to the emerging four contexts revealed four overarching categories that provide a theoretical explanation of the meaning of being a PWA in Nigerian society. Each category was explored by investigating the attributes and properties relating to the data context, processes, and conditions within which the incidents of experiences occurred.

5.3.1 Being in a tug of war

The conceptual category "being in a tug of war" is an *in vivo* code constructed by one of the participants. It appears to adequately conceptualise childhood experiences as described by participants in this study. It provides a theoretical explanation to the meaning of being a child with albinism (CWA) in Nigeria as described by the participants. It also answers the question I asked of data, which is, how can participants' description of their childhood experiences be conceptualised?

The data that were used to construct this category were obtained from Besu, Eki and Uma. This category and its properties were located in the context of the participants' childhood experiences within the home environment. I interrogated the data to discover pieces of evidence that warranted the incidents in data. It emerged that the experiences of 'being in a tug of war' was conditioned by low level of parents' education¹⁰. Comparison of incident-to-

¹⁰ This inference was made possible with additional data obtained through theoretical sampling. Low level of education in this context meant parents who have achieved only the primary level of education

incident coding between similar experiences from different participants provided a description to the processes and the conditions that shape the conceptual category of ‘being in a tug of war’. The descriptive properties that emerged from the data in relation to the category were:

- a) Witnessing tension and marital breakdown between parents
- b) Unequal distribution of parental attention
- c) Unfair burden of domestic tasks
- d) Being denied educational opportunities
- e) Being subjected to physical abuse

Exploring these properties, it emerged that ‘being in a tug of war’ is a conceptual description of the constant struggle and challenges that a CWA contends with as a result of parental unacceptance of albinism which results to unfair treatment of the CWA in the home environment.

a) Witnessing tension and marital breakdown between parents

This property was constructed through questioning the data to reveal what the participants were telling me. It transpired that they were telling me that under the condition of their parents’ lack of understanding and acceptance of their condition, their childhood lives were characterised by witnessing tension and marital breakdown between their parents. Labelling this property as such provided description of context and conditions under which being in a tug of war occurred and the consequences thereof. Participants witnessed tension between their parents which was an experience that some participants attributed to the fact that their father’s low level of education¹¹ might have contributed to the lack of understanding and

¹¹ This inference is drawn from data obtained in Uma and Eki’s stories, see Presentation of Finding section 6.2

acceptance of their condition, and thus, could be argued as the basis for struggling to accept the reality of having CWA.

Data from these three participants revealed that marital breakdown between their parents meant the departure of their mothers from the family home. In this case, participants were left in the custody of their fathers and stepmothers – a change in their life that they admitted left them vulnerable to unfair treatment and abuse. The manifestations and variations of participants' vulnerability was investigated during subsequent *fact-chasing* interviews.

b) Unequal distribution of parental attention

I went through the process of iteration to discover other incidents that constitute participants' realities of 'being in a tug of war'. It emerged that 'being in a tug of war' also conceptualises the experiences of unfair treatment which necessitated the need for the CWA to constantly negotiate for equal treatment within the home environment.

c) Unfair burden of domestic tasks

Similarly, participant's narratives of 'being in a tug of war,' were replete with recollections of abuse in the family home by being apportioned an unfair burden of house chores and domestic tasks.

d) Being subjected to physical abuse

This property captured a range of adverse childhood experiences. While these experiences could happen to any child, the differentness of CWA and the societal myths ascribed to their condition exacerbated their situations. This property was obtained from Uma's story. Her data highlighted incidents whereby she was physically abused by her stepmother who subjected her to street hawking. She described an incident whereby a man pretending to be a customer raped her while she was street hawking. This participant's experience of sexual

abuse which she believed was because of her albinism sensitised me to explore data from the narratives of other female participants with an additional lens of gender differences.

e) Being denied educational opportunities

The home-life experiences of these participants highlighted the various challenges and disadvantages that CWA are likely to face in a home environment with poor understanding and tolerance of albinism. In addition to the possibility of being unfairly and abusively treated in the family home, data alluded to the fact that their parent(s) did not enrol them in school because they were regarded as lacking the capacity for academic performance due to their visual impairment.

5.3.2 Disadvantaging schooling (and social) systems

Data from all eleven participants were used to construct this category. Whilst the participants did not use the phrase “disadvantaging schooling and social systems,” it emerged that their description of childhood experiences outside the home environment was situated within the schooling environment. The stories of their experiences during their schooling age indicated that their peers picked on them frequently and made them feel like they were the object of curiosity.

Teachers, in turn, did not intervene to stop this behaviour. Instead, some teachers used them as an example in class, thereby, drawing additional unwanted attention to them. CWA have a visual impairment which means they need special adjustments and support in order to create an equal playing field with the rest of their peers. The school did not provide these adjustments thus, creating unequal opportunities for education. Based on all these, I concluded that the entire schooling system as a social institution created disadvantages for PWA. Therefore, the conceptual category “Disadvantaging schooling system” seems to

encapsulate all the elements that not only created educational disadvantages for PWA but also enabled injustices in the school environment.

This category provided another theoretical explanation to the meaning of being a CWA in Nigeria as described by the participants. It also answered the question I asked of data, which is, how can participants' description of their childhood experiences be further conceptualised?

The properties of this category that described the schooling experience are characterised by:

- a) Being an object of curiosity
- b) Being picked on
- c) Struggling with schoolwork due to visual impairment
- d) Being excluded from learning
- e) Dealing with rejection
- f) Being subjected to physical abuse

a) Being an object of curiosity

I considered 'Being an object of curiosity' to be a fitting description of PWA's disadvantaging schooling experiences. Participants felt that peers were giving them excessive unwanted attention, which created an unpleasant schooling experience both on the playing ground and in the classroom. This property was grounded in data from participants, including Eki, Nori, Chojo, Fedizy, and Wales.

Even though the participants did not desire to *stick out like a sore thumb*, the actions of other schoolchildren raised their awareness to (i) recognise being different (ii) accept being different (iii) suffer the effect and consequence of being different. This inference was grounded in the data that Fedizy, Chojo and Nori provided.

b) Being picked on

It transpired that frequent acts of curiosity from school peers always manifested in one form of what is described as bullying by Olweus (2001), which left the participants feeling distressed, unsafe and disempowered. According to Olweus (2001), school bullying is the repeated exposure of a student to negative actions of one or more students. It has been established that bullying can occur physically, verbally and psychologically (Crick & Grotpeter, 1995; Olweus, 1993), all of which were experienced by the participants. Ross' (2003, p.27) expatiated definition of bullying as "intentional and generally unprovoked attempts by one or more individuals to inflict physical hurt, psychological distress, or both on one or more victims" offered some sense of relatedness to the participants in this study. The excerpt below, like several others evidenced the incidents that participants considered to be bullying acts. By iteratively comparing data from participants' stories, it became clear that a conspicuously different physical appearance and seemingly unusual visual tendencies were the attributes that predisposed the participants to the risk of being picked on and bullied by their school peers.

So far, data have provided this analysis with an understanding of participants' initial experiences of having found themselves in the midst of other children outside the classroom. Further comparison of incident-to-incident codes in the data provided by Wales revealed that there were occasions when teachers either participated or instigated the process of bullying in the classroom.

c) Struggling with school work due to visual impairment

Struggling to do school work due to visual impairment was a common theme amongst all the participants. This signified the systemic failure by the entire schooling system to provide

necessary accommodation for people with visual impairment, thus creating inequalities in access to learning opportunities.

Participants' stories of their visual impairment posed the most significant restriction on full learning participation. Their narration of classroom learning experiences was replete with references to poor vision.

Given that data have suggested that visual impairment disabled participants from fully engaging with schoolwork, the next detail to explore was the role of teachers and availability of support to improve learning experiences more especially as participants were already being unjustly treated by peers.

d) Being excluded from learning

Participants did not say that they were excluded from learning, but the actions and attitude of teachers made it difficult for them to have equal access to learning opportunities. This descriptive property emerged from data from all the participants, and it evidences the incidents that described teachers' attitudes and actions that left them feeling excluded from the opportunities for learning. Participants explained that the school did not offer them any learning aid, nor did the teachers offer any additional learning support considering their struggle with school work because of visual impairment.

It should be noted that the schooling system doubles as a social institution. Drawing from data, it was inferred that the schooling system constituted a disempowering and disadvantaging social environment for participants given various experiences of injustices in the form of bullying and struggling with schoolwork.

e) Dealing with rejection

The analysis revealed that being different disadvantages PWA not only educationally but also socially. Participants explained that there were times when peers avoided social interaction with them due to their differentness. Participants found it particularly challenging to deal with rejection at an adolescent age that is conventional considered to be a difficult stage of development without the stigma of being different (Hall, 1904; Spear, 2000).

5.3.3 Suffering double tragedy

The expression used by one of the participants in this study was adopted as an *in vivo* code to further conceptualise what it means for them to be PWA in Nigerian society. This category was situated in the adulthood life-stage of the participants. The concept of “Suffering double tragedy” provides a theoretical explanation to the meaning of being a person with albinism in Nigerian society. The properties that provided description of incidents, processes and condition that gave rise to the category are:

- a) Experiencing exclusion from employment on the basis of social identity
- b) Double tragedy as it relates to romantic relationships
- c) Being taken advantage of as a female with albinism
- d) Inhibiting social wellbeing outcomes

a) Experiencing exclusion from employment

All the participants attested to experiencing discrimination and rejection from employment opportunities. They believe this was because the Nigerian society continues to use their physical appearance and visual impairment to exclude them from the working environment.

Collectively, data implied that the social institutions of employment are unfairly configured to exclude PWA, rather than finding ways to accommodate their disabilities.

b) Double tragedy as it relates to romantic relationships

This property emanated from data that were obtained from female participants. They maintained that the Nigerian society does not regard females with albinism as being desirable for genuine romantic relationships but only to exploit their vulnerability.

c) Being taken advantage of as a female with albinism

This property follows the participants' description of their romantic relationship experiences. Data suggested that being a female with albinism (FWA) increased vulnerability to sexual abuse, exploitation, and oppression by men in the Nigerian society. The incidents of men making sexual advances to females do not occur to females with albinism only; however, the stories of female participants in this study suggest that the risks of being sexually exploited and raped are increased for FWA.

Comparing incidents in the stories of two participants in this study – Uma, and Besu illustrated different forms in which men are likely to take advantage of FWA. They explained that whilst some FWA might not experience direct bodily harm such as rape, they remain susceptible to experiencing but romantic relationships that are characterised with deceit. They explained that some Nigerian men targeted them for sexual exploitation and not for genuine relationship interests.

d) Inhibiting social wellbeing outcomes

During the interviews, all participants described incidents of feeling excluded and isolated from social networks which in effect inhibit their social wellbeing. According to participants, these difficult social experiences were attributed to the undesirability of their physical appearance.

Data from Wales's story illustrated the implications of social isolation on PWA. He mentioned "having bad days" when negative social experiences 'get to him'. His narrative drew me to explore the conceptual meaning of his recollection of "*it gets to [me]*" and "*I have bad days*". I was sensitised to ponder on two questions:

- (i) What constitutes the participants' expressions of "*it gets to me*"?
- (ii) What is the meaning and implication of having a bad day?

After carefully examining the codes in participants' excerpts comparatively for context and meaning (see Table 4 below), it emerged that the abstract concepts of "*it gets to [me]*" and "*having a bad day*" are mutually inclusive.

Table 4: Conceptual meaning of social experiences

Social Experiences: effects and consequences	
It gets to me	Having a bad day
<p>"It affects me in many ways because I feel inferior [<i>Damaged self-esteem – speaks to wellbeing</i>]; At times, I will say "Why did God even create me this way?" [<i>Questioning self-identity</i>]</p> <p>"You keep losing your confidence and it does happen to me [<i>Losing self-confidence – speaks to wellbeing</i>]. I think I've missed out a bit of opportunity in life because of that" [<i>Effect: Losing life opportunities</i>]</p>	<p>"At times, I decide not to make friends with others, not to associate with other people [so as] to avoid discrimination [<i>Effect: Intentional withdrawal due to perceived discrimination; amounts to social isolation</i>]"</p> <p>"I don't socialise much because I'm scared not to be embarrassed [<i>Effect: Intentional withdrawal; amounts to social isolation</i>]"</p>

<p>“Sometimes when I am going to town, I would look at myself and start feeling bad” [<i>Suggesting feelings of being inferior – speaks to wellbeing</i>]</p>	<p>“I don’t cope well - it’s really hard for me [<i>Disenabling resilience</i>]. Instead of going out to face challenges, I won’t go [<i>Effect: Intentional withdrawal; amounts to social isolation</i>]</p>
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The unifying process of these concepts begins when society regards and treats PWA unkindly because of unfairly ascribed social identities; the process of “*it gets to me*” culminates in various feelings of damaged self-worth and loss of sense of belonging. The process ends by “*having a bad day*” characterised by loss of self-esteem and self-worth, in addition to an intentional withdrawal from social engagement in order to avoid interactional situations that may otherwise expose them to society’s attention and ridicule. Given that GT analysis methods are rooted in examining processes and consequences (Dey, 2008), ‘Inhibiting social wellbeing’ was conceptualised to interpret and embody the processes and outcomes of “Having a bad day”. Thus, “Inhibiting social wellbeing outcomes” was characterised as a property of the category ‘Suffering double tragedy’ as is seen in Section 6.6.

5.3.4 Coping with ‘being different’

A closer interrogation of data revealed that participants have discovered strategies to cope with the realities of being different. These coping strategies serve as ongoing mechanisms to overcome the trauma of past experiences and to build resilience against the injustices that participants face presently as adults. These coping mechanisms epitomise the commonality of determination for participants to attempt to thrive in the Nigerian society. The properties that constitute this category are as follows:

- a) Coping with negative learning experiences
- b) Joining the Albino Foundation
- c) Injuring self and retaliating name-calling
- d) Having faith and engaging in church activities
- e) Relying on family for support

5.4 Linking categories

Up until this point, I have attempted to demonstrate how data was examined to develop the categories and their properties using the constant comparative mechanism. Having already stated that my analytical approach to coding follows Strauss and Corbin (1990; 1998), it became imperative to establish a link between the categories in order to begin to have a sense of the emerging theory as a whole. At this point, I had not quite figured out the direction that the data is leading me. However, it occurred to me that linking the categories with each other would give me a clearer path of theoretical direction. I already introduced the concept of axial coding in Section 5.1. For me to gain a better understanding of what is required, I referred to Straus and Corbin (1998, p. 126) where they specified the tasks involved in axial coding as follows:

1. Laying out the properties of a category and their dimensions
2. Identifying the variety of conditions, actions/interactions, and consequences associated with a phenomenon
3. Relating a category to its subcategories [properties] through statements denoting how they are related to each other
4. Looking for clues in the data that denote how major categories might relate to each other

Recognisably, axial coding draws on the derivatives of open coding. As I have observed in my interaction with data, it seemed that I had already begun to lean towards axial coding

even during the processes of open coding (Corbin and Strauss, 2008). The majority of the codes I had constructed already fulfilled the first and second tasks listed above. Once again, I referred to Strauss and Corbin (1990) for guidance on how to satisfy the third and fourth tasks. They propose that participants' narratives be assembled into a scheme that highlights conditions, actions, and consequences. This scheme is accessible when each category is examined with the 'when', 'where', 'why', 'who', 'how' and 'what' questions. The conditions under which participants' life experiences occurred were used to address the questions of when, where, why and how of the incidents that participants had narrated (See Figure 7 below). Examining actions revealed who were involved in these incidents. Lastly, consequences provided details on what may have happened as a result of the incidents.

Life-course	Conceptual Categories How can we explain the experiences?	What constitutes these experiences				Why did it happen?
		Context (Where did it happen?)	Conditions (What situations enabled the experiences?)	Actions (Who was involved?)	Consequences (Effect & Outcomes)	
Childhood	Being in a tug of war	Family home environment	Low level of parents' education	Father's negative disposition towards CWA	Unequal treatment of CWA* Being denied educational opportunities	Society's perceptions underlie the continuum of experiences
Childhood into adolescence	Disadvantaging schooling (and social) system	Schooling environment	Unfairly configured schooling environment	Teacher's lack of empathy and support Peers' unkindness	Negative schooling and learning experiences	
Adulthood	Suffering double tragedy	Working environment.	Unfairly configured working environment.	Employers and unfair recruitment policies.	Exclusion from employment. Social isolation.	
		Social environment	Misinformed perceptions of albinism	Society ascribes disabling social identities to PWA	Increased vulnerability for FWA*. PWA* are disempowered	
CWA* = child/children with albinism. FWA*= Females with albinism. PWA*= People with albinism						

Figure 7: an illustration of the life-course experiences of participants that may be used as a conceptual framework to understand and explain what it means to be a PWA in Nigeria under the prevailing conditions.

Figure 7 depicts a continuum of experiences from childhood to adulthood. Even though these experiences occur at different stages in life, the factor linking the categories together can be attributed to society's perception of albinism which forms the basis for societal intolerance and the myriad of consequential disadvantages for PWA. Experiences in the home environment feel like 'being in a tug of war' because parents struggle to come to terms with the realities of having children with albinism (CWA) which further leads to the deprivation of rights for the CWA. When asked, participants implied that the social construction of albinism is such that PWA are undesirable in the Nigerian society because of their unusual skin colour, physical appearance and severe visual impairment. In their opinion, they believe that their parents' low level of education contributes significantly to their adherence to such social constructions. Similarly, we can identify the effects of societal perception in the schooling environment. Peers and teachers alike treat CWA in ways that infringe on their rights to feel secured and accepted in school. As adults, the enormity of societal perception is felt in unquantifiable measures. The seeming undesirability perception of PWA is apparent in employment policies that do not support equal opportunities and disability support for recruitment. Furthermore, the extended social environment through its actions, continues to marginalise PWA (See Chapter 6 for data to support these inferences).

5.5 Identifying a central category

Bringing the research question of "What does it mean to be a person with albinism in Nigeria?" back to focus, it became necessary to delineate the meaning and impact of these experiences on participants' definition of themselves in the Nigerian society. This next step of analysis required the integration of data.

Corbin and Strauss (2008) proposed that data integration in grounded theory is predicated on identifying a central category that represents the core of the research study. According to them, the central category should have the analytic power to explain and link all categories theoretically. I recognised that while the idea of a central category is not entirely fundamental to Charmaz's constructivist grounded theory, her proposal of a "conceptual category" (Charmaz, 2006; p. 91.) bears similar meaning to that of Corbin and Strauss' (2008) idea of a "core category" (p.104). The quest to identify a central category challenged me to revisit the initial codes and memos for clues. With the participants and their stories in mind, I pondered on the following questions:

- (i) Why do participants have these experiences?
- (ii) What is the fundamental reason for these experiences?
- (iii) What phenomenon do these experiences represent?
- (iv) What is this a study of?

As a guide to conceptualise the central category, I referred to Strauss and Corbin (1998) for guidance. They propose selective coding as the process of integrating data for the emergence of a theory. Selective coding requires re-examining the initial codes and treating them to a sort of distillation process to sieve out the excesses that contribute no conceptual meaning. To achieve this, Charmaz (2006) recommends focusing on the most frequent occurring codes across the expanse of data as these are likely to offer a theoretical concept to the phenomenon.

In the course of data collection, participants implicitly and explicitly used the adjective "*different*" to describe how they feel and identify themselves in the Nigerian society. As I interrogated data, it became evident that the most significant unifying characteristic of all participants is their physical appearance which makes them immediately identifiable and sets

them apart from other members of the society in Nigeria. Reflecting on Glaser's (1978) prescriptions for theoretical coding, I conceptualised '*Being Different*' as the central category that most accurately depicts the difficult life experiences of what it means to be a PWA in Nigeria. Thus, *being different* in terms of physical appearance and visual impairment is the answer to all four questions stated above. Participants' verbatim narratives that supported the identification of the central category are as illustrated in Figure 8 below.

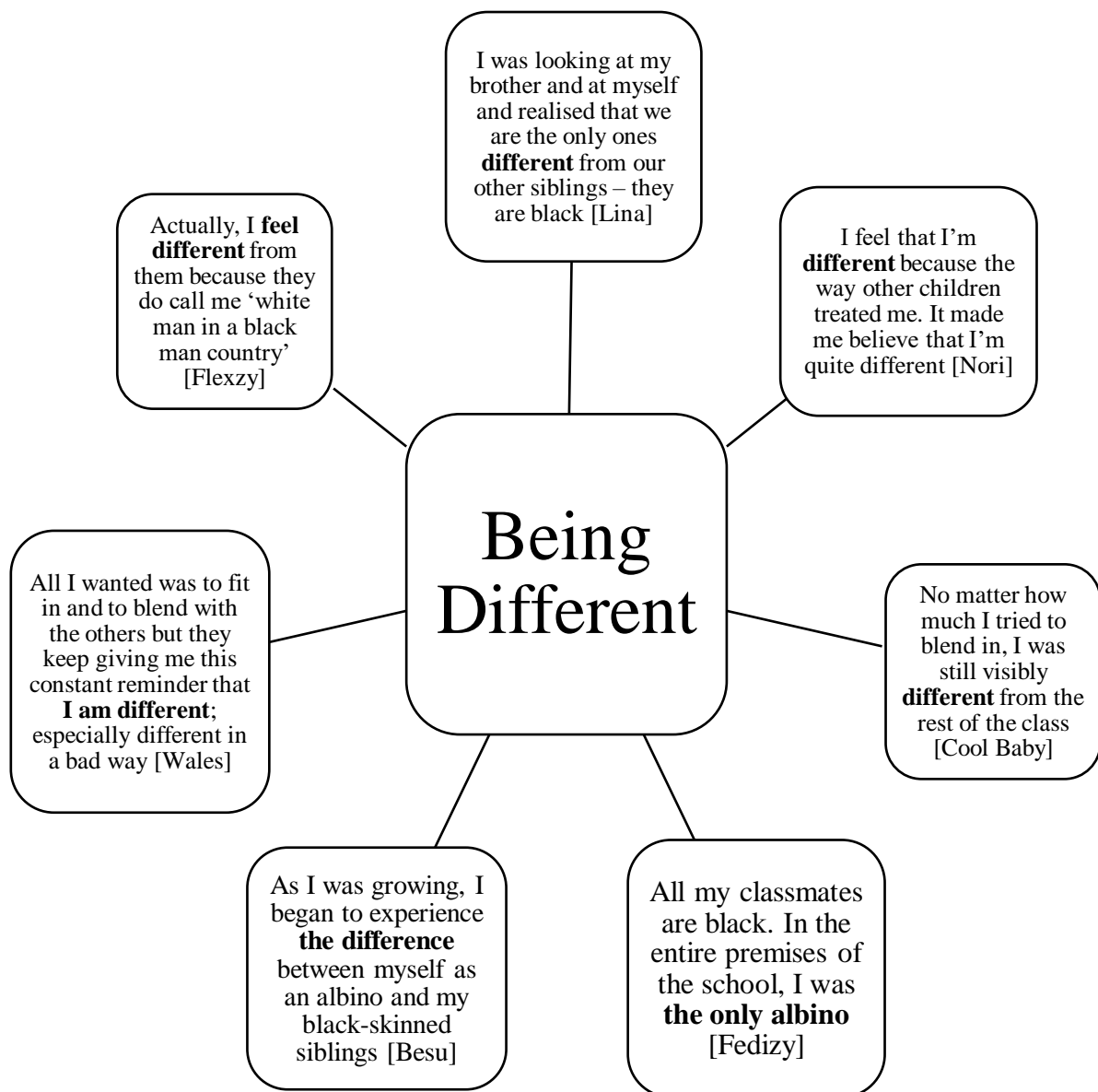


Figure 8: Participants' conceptualisation of "Being different"

Recognisably, the experiences that participants used to reflect their feeling of ‘being different’ could be located in childhood. I wondered if it was enough to theorise ‘being different’ as a sum of the meaning of life experiences from childhood to adulthood. I asked myself if ‘being different’ tells a partial or complete story of what it means to a PWA in Nigeria. A nagging question as I wrote memos is “would *being different* hold true in light of adulthood experiences? The need to fill the gaps in this central category as a means of validation was my gateway into conducting theoretical sampling.

5.6 Theoretical sampling

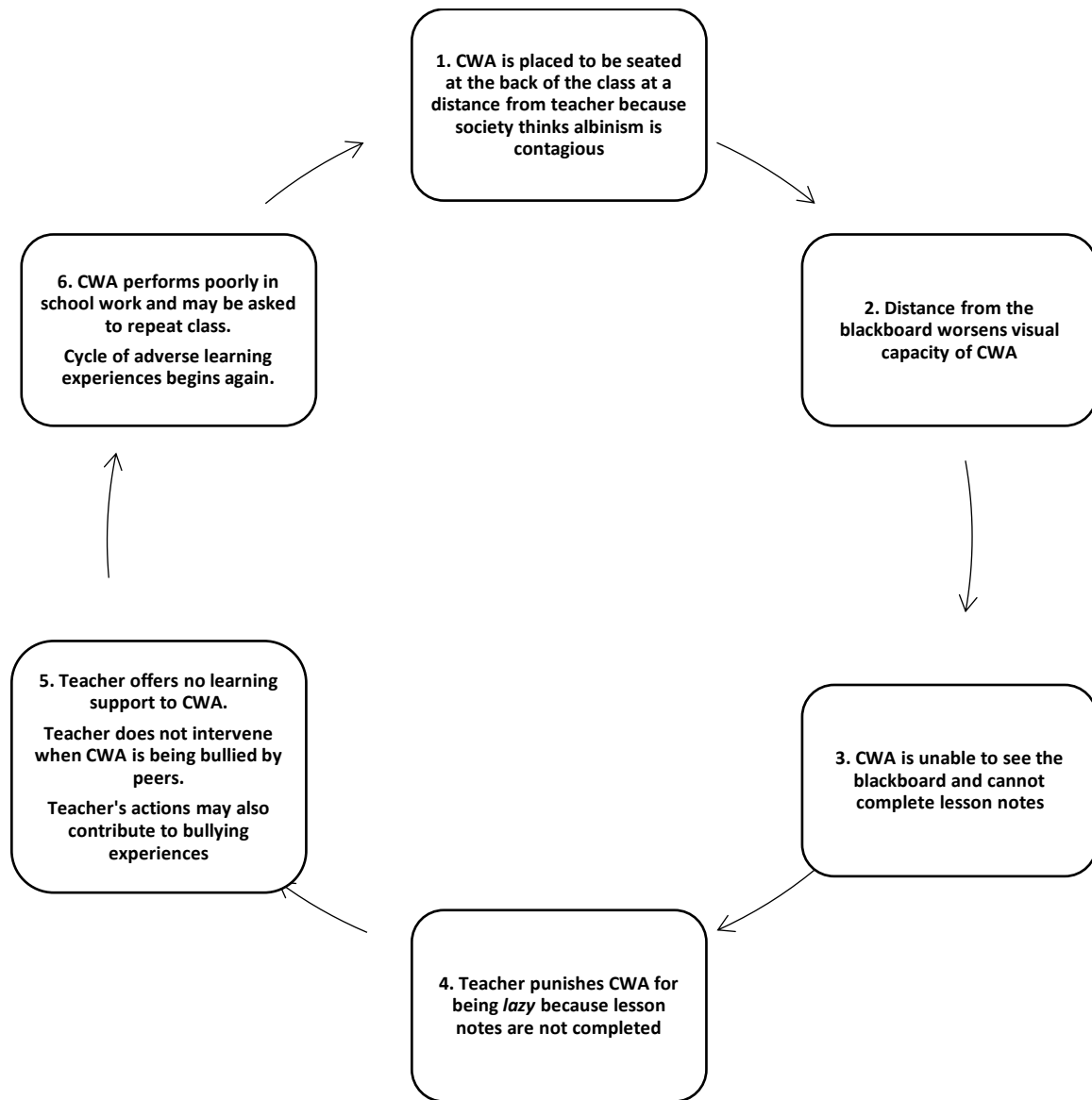
Up to this point, data have led me to develop a central category of ‘being different’ and four subcategories that consolidate the continuum of experiences from childhood to adulthood: (1) being in a tug of war, (2) disadvantaging schooling (and social) system, (3) suffering double tragedy and (4) Coping with ‘being different’. In addition to the misgivings I held about the theoretical reach of ‘being different’, I realised that some properties of categories ‘being in a tug of war’ and ‘disadvantaging schooling system’ were not sufficiently refined. I drew on Charmaz’s (2006) and Strauss and Corbin’s (1998) recommendation for theoretical sampling, whereby, I strategically collected specific data aimed to develop and refine properties of the categories. Offering specific guidance, Charmaz (2006, p.103) states that “memo-writing leads directly to theoretical sampling” as I demonstrated in Figure 5. Thus, I referred to my memos and was able to identify gaps in the initially collected data. This necessitated the need to contact five participants and ask additional focused questions. These additional interviews occurred over the telephone between April and May 2019 as I was in Chester writing up this thesis.

Under category ‘being in a tug of war’, Eki had mentioned that witnessing tension and marital breakdown between her parents affected her a lot while Uma claimed that this

experience “only brings problems for the child”. Additional data from theoretical sampling suggested that the event of marital breakdown between their parents left them vulnerable to being maltreated. Vulnerability in this context manifested differently even though the effect remained similar. Eki believes that her mother’s absence left her in want of the support she needed to build the self-confidence that she lacks even now that she is an adult. She said she felt unwanted in the family home because her father deprived her of his attention. Asking if the passage of time has had any influence on her father’s disposition towards her, Eki replied that her experiences in childhood continue to put a strain on her present relationship with her father and her siblings. In another perspective, Uma stated that she would not have been subjected to street-hawking and experienced being raped if her mother had not left the family home. Uma added that these experiences have left her with anger issues which she struggles with presently as an adult. These additional pieces of data offered plausible evidence to infer that the consequences and meanings participants attached to their experiences in childhood are still applicable and effective in their present lives as adults. Thus, this validates ‘being different’ as a central category to understand and explain participants’ realities in childhood and in present day as adults.

In the category of ‘Disadvantaging schooling (and social) system’, participants had talked about experiences of difficulties to see the blackboard, being bullied by school peers, and failure of the school to provide equal opportunities for learning. However, their initial narratives did not quite capture the role of their teachers. Earlier on in the memo presented in Figure 5, I had contemplated the role of education on people’s perception and treatment of PWA. It occurred to me that identifying teachers’ role would be critical for the recommendations that this study is likely to proffer. This realisation contributed to my considerations for theoretical sampling.

New data from these subsequent interviews border on the social identities that teachers are likely to ascribe to PWA. In the opinion of participants, their teachers always perceived them to be lazy because they always had difficulties completing lesson notes and catching up with the rest of the class. Participants had similar opinions to elaborate on the role of teachers in their learning experiences. They recognised that their teachers were also part of the larger society even as they remained designated gatekeepers and trustees of the learning environment. This implies to mean that their teachers were not always able to bracket out societal perceptions about albinism from influencing how they fulfilled their responsibilities to students with albinism. Thus, it can be inferred that teachers were in breach of their social contract as representatives of both the parents and pupils in the school environment. Teachers' indifference to the plight of CWA as established by data is suggestive of abuse of power as designated trustees to school children. Pooled comparative data revealed a pattern to illustrate the failed responsibility of teachers as shown in Figure 9 below.



*Figure 9: Pattern to illustrate the teacher's role in school experiences *CWA = Child with Albinism*

In addition to fully understanding the processes of the properties that constitute 'Disadvantaging schooling (and social) system,' theoretical sampling afforded me the opportunity to ask participants what overall meaning they have made of their life experiences. Participants' answers to this question were relayed in implicit and explicit terms. Their answers were synthesised into an overall theoretical concept of what this study had been about. As if to echo each other's opinion, 'being different' holds a plausible central category

to anchor the sum of participants' experiences from childhood to their individual on-going realities.

This abductive reasoning rests on the data that was obtained from Ella when she implied that PWA are still experiencing the realities of 'being different' because the Nigerian society has not changed:

“Nothing has changed. Or should I even say it's getting worse” - Ella

Beyond this stage, I reviewed my memos for any flagged gaps and no new data emerged from subsequent *fact-chasing* attempts. It would appear that I had attained what Dey (1999) calls “theoretical sufficiency” (p.257). Theoretical sufficiency in its literal sense means that additional data no longer contributes to the analytical robustness of the categories that have emerged in this study.

Participants attributed the way they interact with society and family to their *being different* in the context of the Nigerian population as illustrated in Figures 7, 8 and 9. The interpretation of participants' life experiences that was subsumed under *Being Different* stemmed from knowing that they are continuously treated differently by the Nigerian society because of the unusual white/pale colour of their skin in a predominantly black African society and their visual impairment. Thus, their appearance and their visual disability disqualified them from socially acceptable characteristics of a Nigerian child and later, adult. Identifying *being different* as the central category also proved credible to understand and interpret the relationships between participants' experiences as they transitioned from childhood to adulthood as illustrated in the conceptual framework Table 5.

Table 5: Conceptual components of ‘being different’

Phenomenon: What is this a study of?	Life course and context	Conceptual categories	Descriptive properties: What constitutes these experiences? (What happened? Why did it happen? Actions of Who was involved and Consequences)	Society's perceptions underlie the continuum of experiences
Being different	Childhood (experiences within the home)	Being in a tug of war	Witnessing tension and marital breakdown between parents	
			Unequal distribution of parental attention	
			Unfair burden of domestic tasks	
			Being subjected to physical abuse	
			Being denied educational opportunities	
	Childhood (experiences at school)	Disadvantaging schooling (and social) system	Being an object of curiosity	
			Being picked on	
			Struggling with school work due to visual impairment	
			Being excluded from learning	
			Dealing with rejection	
	Adulthood	Suffering double tragedy	Experiencing exclusion from employment opportunities	
			Double tragedy as it relates to romantic relationships	

			Being taken advantage of as a female with albinism	
			Inhibiting social wellbeing outcomes	
		Coping with ‘being different’	Coping with negative learning experiences	
			Joining the Albino Foundation	
			Inuring self and retaliating name-calling	
			Having faith and engaging in church activities	
		Relying on family for support		

5.7 The emerged substantive theory

Having attended to all unresolved questions in the categories and established *being different* as centrally characteristic of the participants, I advanced onto the stage of theorising as per Strauss and Corbin's (1990) second level of qualitative data analysis, that is, to build a theory using advanced levels of abstract interpretation as stated in Section 5.1. To this end, I leaned on Charmaz (2006, 2014) who contends that a theory is an interpretation that fits the data. Theorising is subjective to the researcher's ability for imaginative understanding and interpretation of the phenomenon (Bryant, 2002). Accordingly, a theory underpinned by constructivist grounded theory should represent and reflect actions, multiplicity of realities and more importantly, should iterate that realities are only true under certain conditions and therefore, are provisional (Charmaz, 2006; 2016). Admittedly, the central focus of this study is to generate a substantive theory that aims to proffer the most straightforward interpretation of the phenomenon of *being different* as a person with albinism in Nigeria.

Being Different as a central category embodies the various contextual processes of all the other categories that have emerged from data analysis. In the context of this study, *Being Different* is a matter of action and effect. All through this chapter, data have inferred that *Being Different* is the derivative of the transactional actions of members of the society within and outside the family unit. These transactional actions are further enabled by the unfair configuration of social institutions in Nigeria, beginning in the family unit and extending into the schooling and working environments, thereby facilitating multiple manifestations of social injustices. Transactional actions are made evident in societal perception of PWA and ascribed social identities. Goffman's (1963) pioneering work on stigma offers a substantial framework with which the emerged theory could be explained. The sum of Goffman's (1963) points of view as documented in his 'Notes on the Management of Spoiled Identity' pivot on

how society perceives and treats certain individuals based on their differentness. As is later discussed in Section 7.5, some of the ways by which participants cope with the daily experiences and challenges of being different could be located in Goffman's work. Based on this premise, and bearing in mind Strauss and Corbin's (1998) definition of a theory as "a set of well-developed concepts related through statements of relationships, which together constitute an integrated framework that can be used to explain or predict phenomena" (Strauss & Corbin, 1998, p.15), the substantive interpretive theory that has emerged from data analysis is as follows:

"I contend that the disadvantaging and unfair attitude and action by society and social institutions toward PWA, based on their differentness constitute a violation of social justices as conceptualised by Mabhala (2014). Mabhala (2014) conceptualised social justice as the idea of creating a society or institution based on the principles of equality and solidarity, that understands and values human rights, and that recognizes the dignity of every human being. I argue that these injustices are driven by unfairly configured social institutions based on the social constructions for PWA in Nigeria. These social injustices are shaped by the actions of significant others¹² and manifests as ongoing realities of stigma, managed by different mechanisms of resilience".

¹² Significant others in the context of this study is an umbrella term which encompasses all members of the society whose actions directly or indirectly shape participants' life experiences to include: family, school peers, teachers, employers and colleagues, romantic partners, and policymakers

The generated theory can be broken down into four inter-related elements:

- (i) Being in a tug of war
- (ii) Disadvantaging schooling (and social) system
- (iii) Suffering double tragedy
- (iv) Coping with ‘being different’

The four components of the generated theory allude to the perpetration of social injustices on PWA in the Nigerian society. Rawls (1971) envisions a society in which justice as fairness is the foundational virtue of all social institutions. Based on this premise, Rawls’ (1971) theory of justice proposed the principle of equality as a mechanism to enable equal and fair access to primary social goods to the greatest benefit of disadvantaged members of the society.

Relating this philosophy to this study, primary social goods include learning and employment opportunities both of which data have indicated that PWA in Nigeria are restricted from fully accessing on the basis of their visual impairment and physical appearance. Since ‘*Being different*’ is an attribute of albinism as constructed by participants; thus, the life experiences of PWA as being different is characterised with multiple experiences of social injustices in Nigeria.

5.8 Summary

This chapter explained the grounded theory techniques and procedures used to analyse collected data for this study. For guidance on data conceptualisation, data integration, and theorising, it relied on the works of Charmaz (2006; 2014), Corbin and Strauss (2008), as well as Strauss and Corbin (1990, 1998).

In order to achieve the third and last aim of data analysis as stated in Section 5.1, the next chapter presents the descriptive findings of this study as narrated by participants.

Chapter 6: Presentation of Findings

6.1 Introduction

This chapter presents the findings that were used to construct the substantive theory of ‘being different’ in the previous chapter. In consistence with the analysed data, the findings have been categorised in a descriptive order that trails the life-course experiences of participants as persons with albinism (PWA) in Nigeria. This is because participants have narrated their stories in a chronological order that offers a sense of temporal insight into the realities of being PWA given the conditions and contexts within which they have situated their experiences. Charmaz’s (2004; 2006) constructivist grounded theory (CGT) methodology prides itself in the tradition of acknowledging participants as partners in the construction of meaning. Thus, researchers owe participants the responsibility of interpreting and dissemination data in a way that preserves participants’ narration of their stories.

Participants have shared their life stories in a chronological order that begins from childhood onto adulthood. If it made sense to them to share their stories in this manner, then, in keeping with the tenets of CGT, it becomes my moral duty to relay their stories accordingly. Adopting this approach to the presentation of findings is particularly important to the emerged nature of this study given its potential to inform social reform at different levels. Even though ‘being different’ has emerged as the theoretical concept that encapsulates the experiences of PWA as a whole, I considered it worthwhile to explore the components of *being different* in their fragmented states. This is because the required social reform needed to alleviate the plight of PWA in Nigeria requires an interdependent multisectoral collaboration between all social institutions including the family, education, religion, the government and the society itself being a conduit for social practices and relations. My point of view here is that the effective and sustainable appropriation of social equity for PWA requires each of the social institutions

to identify and locate their specific roles in the chronological components of *being different*. Positioning my argument this way, if this study catches the attention of those who have the socio-political power to drive social reform, then it is hoped that the interventions to ameliorate the experiences of PWA in Nigeria would be targeted to address their challenges at specific stages in the life-course of any individual with albinism regardless of age.

Extracts from participants' biographical stories span from childhood to adulthood experiences. The narratives revealed that participants developed a level of self-perception of being different in early childhood between ages four and seven. The data revealed three contexts that shaped their childhood experiences:

- Relationship with parents
- Social experiences
- School experiences

Participants explained that their perception of being different became more apparent at around age four when they started pre-school. They became aware of how different they appeared physically from their peers at about the same age.

As explicated in the previous chapter, the central category that embodies what it means to be a PWA in Nigeria is '*Being different*'. Given the contexts listed above, the conceptual categories that provide a theoretical explanation of '*Being different*' are as follows and each of them would be explored sequentially along the dimensions of their respective properties as presented in Table 6 below:

Table 6: Conceptual categories of ‘being different’ and its descriptive properties

Conceptual categories	Descriptive properties
Being in a tug of war	a) Witnessing tension and marital breakdown between parents
	b) Unequal distribution of parental attention
	c) Unfair burden of domestic tasks
	d) Being subjected to physical abuse
	e) Being denied educational opportunities
Disadvantaging schooling (and social) system	a) Being an object of curiosity
	b) Being picked on
	c) Struggling with schoolwork due to visual impairment
	d) Being excluded from learning
	e) Dealing with rejection
Suffering double tragedy	a) Experiencing exclusion from employment opportunities
	b) Double tragedy as it relates to romantic relationships
	c) Being taken advantage of as a female with albinism
	d) Inhibiting social wellbeing outcomes
Coping with ‘being different’	a) Coping with negative learning experiences
	b) Joining the Albino Foundation
	c) Inuring self and retaliating name-calling
	d) Having faith and engaging in church activities
	e) Relying on family for support

6.2 Being in a tug of war

*“When we were given birth to, my daddy was wondering why. He was blaming my mom that she’s the one that brought albinism and my mom would tell him too that she doesn’t know. It was a **tug of war** that my dad even abandoned the home and refused to take the responsibility of me [and] the last born who is [also] an albino” - Uma*

Participants in this study traced their realisation of ‘being different’ from their childhood experiences. For some participants, being a child with albinism (CWA) felt like *being in a tug of war*. The conceptual construct of what it means to be a CWA in Nigeria began at the stage of internalised self-perception within the home environment as mediated by parents’ attitudes and treatment. The participants whose stories were used to construct this category implied that their experiences of *being in a tug of war* occurred under the condition of their parents’ lack of understanding and acceptance of albinism which they attributed to low level of education.

“You know when you are not very educated; you accept anything that the culture tells you. Maybe he was thinking that we won’t be useful in life, so he didn’t care much. But if he had gone to school, may be things would be different” - Uma

“Me I believe it is because he did not really go to school. And he was listening to all those people from the village then. Ehn Ehn! They were always telling him it’s my mom’s fault for having albino. And that we won’t last long because we are weak – all those things. If he went to school, he will have known better than to be listening to all that nonsense things” - Eki

6.2.1 Witnessing tension and marital breakdown between parents

The participants identified the relationship between CWA and their families as the foundation for initiating awareness of being different and influencing self-perception and adjustability during childhood. They maintain that parents' understanding of albinism determines the kind of relationship a CWA will have with parents and siblings.

Besu is from a polygamous home. Besu's father had multiple wives, and she has stepsiblings all of who have pigmented skin. However, Besu's mother had four children, three of whom have albinism including herself. Besu started realising that she was different from other members of her family when her stepsiblings began calling her names. This awareness was further heightened by the adverse skin reactions she experienced as a result of exposure to sunshine while farming outdoors with her father and siblings. She explains that:

“In my family, my stepsiblings always insulted me - they will call me names. My father made all of us to join him in farming. Whenever [the] sun hits us the albino children, our skin will redden and become inflamed. We had boils come out of the inflamed spots; when they are healed, they turn black – that's why I have spots on my body. As I was growing, I began to experience the difference between myself as an albino and my black-skinned siblings. I saw the difference between albinos and black-skinned people because my black-skinned siblings did not feel any of the pains I felt on my skin” - [Besu]

Besu further narrates how the occurrence of albinism caused disharmony and the eventual marital breakdown between her parents:

“My mother told me that my father accused her [of] bearing albinos and that my father hated her because of it. She also told me that my grandmother did not

relate with her as kindly as she related [with] the other wives. When my mother could not bear the bad treatment any longer, she left and took the last born with her” – [Besu]

Uma and Eki believe that poor understanding and lack of acceptance of albinism by the parents led to the breakdown of their families as Uma explains:

“My daddy wondered why I and my sibling were albinos. He blamed my mom for bringing albinism to his lineage. My parents later separated and I was left with my dad. He abandoned us and refused to take the responsibility of my welfare” – [Uma]

Eki also attributed her family breakdown to her parents’ poor understanding of her condition. She explains:

“My mom did not have the opportunity to grow with us when we were coming up which really affect[ed] me a lot - she left us at a tender age.

My mom gave birth to the first and second issue, and there was no problem. But when she gave birth to the third who is an albino that was when she started having problems with my dad. According to my mom, when she gave birth to me, my father was saying “Ha! What’s this you are carrying? What’s this” - [Eki]

Chojo, on the other hand, explained that it was her mother who could not come to terms with albinism:

“I’m the first born in my family. According to my father, he said on the day of my birth, he called people together for jubilations which lasted three days. My Mumsie – she did not even like me at all. One naira, my Mumsie will not give

[me]. It's only my dad that's doing everything: soap, money, school fees, everything. And my father was not happy with her at all – they used to argue a lot” - [Chojo]

For Flexzy and Fedizy, their stories appear to suggest that the care and attention they received from their parents provided them with confidence to overcome their siblings' bad behaviour towards them.

“Well, my growing was well. My dad and my mom took care of me very well. My siblings - they do call me names. Each time they do call me names, they go under punishment from my parents. Actually, I feel different from them. I do feel different from them. I feel sad, but after some time, they do come to apologise” - [Flexzy]

“[My parents] – they all take me along. Instead of mocking or doing some things that I don't like, they will just be patient with me in all my doings; they will give me advice how to listen to the black ones that are mocking me. I got enough support from them; very well” - [Fedizy]

The majority of participants who had a positive relationship with their parents [and siblings] came from well-educated families. They attributed their parents' good understanding of their condition to their level of education. This is how Wales describes his relationship with his parents and sibling:

“My parents were very supportive maybe because both of them are well educated. My mother in particular always used to be there for me. I had a very stable –you know- family life and they believe that I could achieve or attain any

level which I wanted – so they were very supportive. I feel I'm just blessed because my parents actually helped me out” - [Wales]

Nori shared the same experience and conclusion. She explained that:

“...fortunately enough, my dad is educated – he has a Ph.D. in computer/mathematics, and my mom is educated to a level – HND [higher national diploma]; so I will say I come from a literate and supportive family” - [Nori]

The key points that emerged from this property are: parents' poor understanding of the condition resulted in family breakdown and disharmony amongst the siblings. The parents' good understanding of albinism helped to equip participants with confidence to deal with negative behaviour from others. It also appears that parents' level of education had an influence on parental understanding and acceptance of the albinism.

6.2.2 Unequal distribution of parental attention

For participants who witnessed tension at home, their parents' difficulty to come to terms with having a CWA was also expressed in differential treatment which was often to the disfavour and disadvantage of the CWA. For example, Eki implied that the lack of attention from her father made her feel different from her siblings:

“My dad had other wives and other children but what my dad could do for other children, by the time I ask him – he will give me an excuse” – [Eki]

Similarly, Uma goes on to explain how her father's unequal treatment triggered her awareness of being different from her siblings:

“And when I go to talk to him (my dad) he’ll chase me away and say I should stop disturbing him. And I wasn’t gaining much respect from my stepbrothers and sisters maybe because they felt I’m not seeing [because] I’m an albino, and daddy wasn’t going to pay much attention. [They were thinking] that they are better than me. That was what I was seeing. I was seeing [thinking to myself] were they better than me?” - [Uma]

6.2.3 Unfair burden of domestic tasks

Uma’s story further implied that she was allocated an unfair burden of domestic chores:

“It became as if I was a slave in my father’s house. I won’t eat at the right time, I’ll be the first to wake. I’ll be the last to sleep, taking care of my stepmother’s children. I was doing all sorts of labour for my stepmother and things my skin wouldn’t have [tolerated]. I’d go to the farm with her and would also be the one to hawk early in the morning. When I’m walking on the road [hawking], I will now be crying telling God that is it because I’m an albino? Why will I continue like this in my own father’s house?” – [Uma]

The last part of the above extract illustrates how the effects of unfair treatment could lead to feelings of desolation and distress for the CWA.

6.2.4 Being subjected to physical abuse

Uma’s story goes further to relay the extent of physical abuse that she suffered in her family home environment. Her story relayed that she was disallowed from socialising with other children. Any attempt to make friends outside the family home was meted with severe physical punishment from her stepmother.

“Maybe I squeeze to run and talk to other children and she sights me from the far coming- [it will result to] the beating of my life. This head [touches her head with reminiscence] - the beating that this head has received is not with ordinary cane – hard things like sticks and wooden ladle”

Uma believes that her stepmother took advantage of the fact that her father was not giving her attention, exploited her vulnerability and compelled her to hawk wares on the streets – an experience that exposed her to being sexually abused by someone who had pretended to be interested in her buying her wares:

“So, this day, I was hawking...before I could talk, he just pushed my hand and was dragging me to the toilet - you know that the power of a man is more than a woman’s; that is how he pressed me down and forcefully used me there. As he used me, I cried, and I went home. I was scared to go home, so I got home late She didn’t open the gate. Rain even beat me from head to toe on [at] the gate there. Neighbours had to beg her - she refused to answer” – [Uma]

6.2.5 Being denied educational opportunities

Uma’s story offered this study considerable insight into the extent of disadvantages that a CWA may experience in a home environment where the parents have little or no understanding [and empathy] of albinism.

“I was staying in my father’s house [and] he would tell me he doesn’t have the money for those things that somebody that is taking care of me should. Daddy refused to send me to school. He said [he does not have] no money; but my younger stepbrothers and sisters, he sent them. He delayed my primary school to the extent that those that we grew up together had gone to secondary school

[and] I was still at home. You know when the parents are not united, it brings only problems” – [Uma]

Uma believes that the marital breakdown of her parents’ marriage contributed to the disadvantages and injustices she suffered.

6.3 Disadvantaging schooling (and social) system

Regardless of the situation with family at home, the commonality of experiences for participants became more pronounced as they engaged with other people at school and in their extended social environment.

6.3.1 Dealing with rejection

Participants indicated that their condition had an influence on their childhood social experiences. Even those who came from supportive families and parents who had a good understanding of their condition are still faced with challenges in socialising with their peers. For some participants, these social experiences served as a realisation of being different. For example, Wales recalls a series of difficult childhood experiences within his social environment whereby he had to face rejection. These experiences triggered his awareness of being different:

“My childhood - it’s never easy for someone – you know – living with albinism especially in Africa where people with the oculocutaneous forms of albinism. So as a child, I had to face a lot of challenges especially. I had issues of people maybe not wanting to play with me. I had issues of peoples’ parents not agreeing to have their children play with me for the fear that it [albinism] might be contracted one way or the other. All I wanted to do was to fit in and to blend with

the others, and they kept giving me this constant reminder that I am different; especially different in a bad way” - [Wales]

Wales is one of the participants who is from a well-educated and supportive family. His story illustrates that despite being from a supportive family, he faced challenges in socialising with peers. He goes on to describe a social event in which the behaviours of his peers served to reinforce his feelings of being different:

“There’s a time – I remember this; I was about nine, and I went for a birthday party. And the girls were sitting on one side and the guys were sitting on one side. So the guys were supposed to pick girls to dance with. So it was now my turn, I picked a girl to dance with. She refused/declined to dance with me; then I went back to my seat - I was feeling very bad. Then it was now the girls’ turn to pick a guy. So I saw the girls – they were now pushing one girl towards me as if it was some kind of punishment. She was struggling that she doesn’t want to dance with me. So I walked out of the room – I was crying” – [Wales]

Wales stated that his experiences of dealing with rejection was sustained all through childhood into adolescence:

“Even when I was in the secondary school and getting to the adolescent stage, I started picking interests in girls; and of course this was an added burden because I had extreme difficulty when my fellow classmates were coupling up. I never had a girlfriend because when I tried once or twice, there was always that rejection. So, it now sort of made me feel –you know- believe “will I ever find a life partner?” – [Wales]

Ella explained that parents of her peers were unwilling for their children to socialise with CWA. Ella recalls a neighbour preventing her children from playing with her and inciting them to call her names. She explains that this experience served to deepen her realisation of being different which initiated a questioning about her self-identity:

“...the woman will say [to my mother] “No. I don’t want this oyinbo [white person]; I don’t want you to carry her close to my children – please stop coming to my compound”. You know then, when [I am] walking outdoors, people will be making [a] jest of [me] that “oyinbo pepper” [a white person with a red skin]. One day, there was a time I sat my mom down. I asked her “Mom, where did you get this type of my colour?” - [Ella]

6.3.2 Being picked-on

Being targeted by peers as a result of unwanted attention was a common experience for all participants. Flexzy describes an experience of being targeted when peers tormented him due to his poor eyesight. He stated that:

“My friends out there they do discriminate [against] me when I go to play football and other things. I remember one time when my mom sent us to look for firewood she’d use to cook. I and some friends went together. So, on our way, we saw a playing ground; we decided to go and join them in playing. So, there’s a merry-go-round. I climbed it; we climbed together. After going a few rounds, they told me to go alone – I don’t know if it’s a plan. When I got on the merry-go-round alone, they started rolling the thing so fast that my eyes started to turn. So I raised [an] alarm that I wanted to come down, but they didn’t agree. They continued doing it, so I just decided to jump off. I hit my arms on the iron frame, and I started bleeding” - [Flexzy]

Participants' experiences of being picked-on took place in the community as much as in the school environment. In most cases, these experiences played out as one form of bullying or the other.

“Then in school, I had issues of bullying; people picking on me; people calling me names. Like in Nigeria – in the south-western part where I come – you know- people call me names like “afin” [meaning belongs to the deity]; the children might surround me and start clapping – you know- could be a bit embarrassing as a child. It was quite hard. I got bullied a lot” – [Wales]

Several other participants relayed similar experiences of being picked-on, especially in school:

“In school, I was the only albino. So, people mocked me; some laughed at me – some called me names. Some will say “oyinbo pepper”. Some will just be laughing at me about my eye-sight; that they should look at me and I will fall into a pit. It affected me so bad. I will sit lonely and start crying”– Fedizy

“In school, my classmates always looked for my trouble. They will be calling me names “Oyinbo pepper [white person with red skin]”. They also mocked my visual impairment and taunted me for not seeing the board” – Besu

6.3.3 Being an object of curiosity

Participants indicated that school experiences influenced their self-perception of ‘being different’ as a result of unwanted attention from their peers. Eki recalled being overwhelmed and distressed by the attention she received from her peers; this excessive attention heightened her awareness of being different:

“When I was in primary one, the first day of me going to school, when we came out for break, all the children - all of them have to gather [around] me- I don’t know if you understand? In the whole school, there was not someone like this [albino] before, I’m the only one. So, while they just gathered there, they [were] just staring at me, I didn’t know what to do - I had to burst into tears, as a baby. So, that first day went like that” - [Eki]

It is clear from this excerpt that Eki’s physical appearance attracted unwanted attention from other children who probably had not come across a PWA until that time. This notion is further reinforced when Fedizy talked of *“I was the only albino. So, people mocked me; some laughed at me – some called me names”*.

The discomfort at school resulting from unwanted attention was one of the shared experiences by the participants in relation to school life. For example, other participants had similar experiences:

“In my school – primary school; when I started the school newly they [schoolmates] will always find my trouble: oyinbo pepper, looku looku pepper, this-that [look at a white person; everyone come and look at a white person]. You know they called me all kinds of name. So when I’m going home, they also wait for me for road to beat me” – [Chojo]

In some cases, participants described incidents of provocation and torment by peers due to their condition and being different.

“You can imagine in a class of twenty persons, and I was the only child that others are laughing at and taunting; they will come and call me names and pinch me to see if [my] skin can turn red” – [Nori]

Lina narrated a similar experience of classroom torment:

“A particular boy in my class always looked for my trouble. He would come [to] sit beside me and would insist that I showed him what I was writing. I didn’t like it whenever he sat beside me. Sometimes, he would cut a sheet of paper, roll it into a ball, throw it at me and ask me to pick it for him – in mockery of my poor eyesight to test if I could see what he threw. Another boy started disturbing me again. He would call two of his friends, and they would always follow me about, calling me names. I didn’t like sitting with anybody – I used to sit alone. On our way home, these boys would throw a football at me, and when I tried to ward them off, they would ask me to identify which one of them threw the ball – to imply that I could not see well enough to identify any of them. I left school because of them” - [Lina]

It is evident from the participants’ stories that in addition to peer-provocation and excessive attention which heightened their sense of being different, some teachers were complicit in the bullying of participants. The stories revealed that teachers were not sensitive to the plight of participants and in some cases, would even use their condition as examples in class. The unintended consequences of this behaviour were further exacerbation of name-calling, ridicule and torment by their peers.

“There was an instance - I was in a private school. My first day in that school, the teacher was now like “This new student that has this complexion, who can tell me what this disorder is called?” So, it now became a big joke; some were saying afin, some people were saying blind bat, and the teacher was now laughing. So he now said the condition was albino; so the other students were saying bambino and all of that. So, it became quite embarrassing”- [Wales]

6.3.4 Struggling with schoolwork due to visual impairment

In addition to their skin appearance, participants made frequent references to their visual impairment as one of the focus of their peer-provocation and ridicule. These excerpts highlighted two aspects of school experiences of PWA in which their visual disability affected their classroom education experiences and further exacerbated unwanted attention. A point of note that emerged from the findings was that the processes involved in struggling with schoolwork are mutually inclusive with their being excluded from learning participation.

“My eyes really disturbed me because I can’t see the blackboard very clear. Some will just be laughing at me about my eye-sight; that I can’t see and I can’t write; I can’t do what the blacks can do” - [Fedizy]

Participants described as a concern, that their visual impairment restricted them from full participation in learning as well as made them a target for name-calling and taunting because of their physical appearance and poor eyesight. Cool Baby sums up the experiences of all the participants in this study:

“My primary school experience is that no matter how much I tried to blend in, I was still visibly different from the rest of the class. I couldn’t see the board as clearly as the others neither could I write as quickly as everyone else. I had different challenges the most disturbing of which was the name-calling on my way to school. My secondary school experiences were not much different from primary school” – [Cool baby]

In addition, the participants identified poor understanding of albinism and lack of support from teachers as having contributed to negative school experiences.

Referring to Wales's story cited earlier in this section of the chapter whereby a teacher used his condition as an example in class: "...the teacher was now like "This new student that has this complexion, who can tell me what this disorder is called?" - this illustrates that the attitude of the teachers significantly and negatively impacted on the CWA. Nori's story also demonstrates that her teachers were not sensitive to how poorly her peers were treating her; this contributed to negative school experiences:

"I was enrolled in a normal mainstream school and there was absolutely no support provided for somebody like me that feel that I'm different because the way other children treated me make me believe that I'm quite different. You can imagine in a class of 20 persons and [I am] the only child that others are laughing at and taunting; they will come and call [me] names and pinch [me] to see if [my] skin can turn red. And [I am] at the corner crying and the teacher doesn't really care or doesn't ask what [my] problems are; and [I] hardly have the courage to walk up and speak to the teacher to say 'Okay. This is bothering me. This set of children are bothering me and all that'. So, I grew up in that scenario. I went to primary school; it wasn't even better in secondary school" -
[Nori]

6.3.5 Being excluded from learning

Consistent with Nori's experiences, other participants also described similar experiences of how lack of support from teachers and poor understanding of albinism served to exclude them from fully participating in classroom learning; they believed this further contributed to their awareness of being different. For example, Ella explicitly states that she was bullied:

"...it was a different experience entirely when I had to leave home for school. So, my primary school was a little bit difficult because then, I was having eye

problems and I got bullied by my classmates because of my low vision impediment. Secondary school, the same thing – you know. So, I can't see the board clearly because my teacher used to put me at the back. Do you understand now? I was always put at the back of the class. Honestly, I don't know why they always put me at the back of the class - I don't know. It was very difficult then. I can't lie" – [Ella]

In a follow-up telephone interview as a means for theoretical sampling, Ella added that her teachers always placed her at the back of the class because they feared contracting albinism and consequently bearing children with albinism. This supports an inference made in the previous chapter that society's misinformed perception of albinism undermines the impact of education in Nigeria. The fact that teachers placed her at the rear of the class despite poor vision further suggests poor understanding of albinism on teachers' part and generally, lack of support for inclusive learning participation. Her separation from other pupils further amplified her sense of differentness.

In addition to the lived experiences of being different, participants' stories also revealed that lack of support and poor understanding of albinism by schoolteachers contributed to poor school performance.

Flexzy recalls:

"When I was in primary school, my dad gave a report and they agreed to give me the front seat, but that [wasn't] enough for me [because] the teachers there did not allow me to shift my seat close to the board. So since I'm not good with my vision, I try with my ears but I always had bad marks" – [Flexzy]

In Eki's case, her struggle with school performance was attributed to visual impairment and lack of support from her teachers:

"When teachers teach us I didn't understand because I could not see. I did not find it funny because I [had] nobody to put me through. I struggled to write my exams" - [Eki]

Another participant recounts how her teachers did not support her with their lesson notes despite being aware of her visual impairment. She recalled that her teachers would call her names and threaten to punish her if she did not complete her lesson notes. This further indicates that teachers were complicit in disadvantaging participants without due consideration for disability assistance.

"When I was in primary school, I did not use to see clearly even when I move closer to the blackboard. Sometimes when I want to read a book, tears come out from my eyes and this made me stop attending school. So my uncle took me to see one of my male teachers, explained my eyes condition to him and suggested that the teacher should always give me his lesson notes to copy which he started doing. When that particular teacher left the school, I had to face another challenge; all the female teachers did not even consider giving me their lesson notes to copy. They would call me oyinbo [white girl] and ask why I wasn't writing down anything during lessons. As soon as they confirmed that I wasn't writing anything down, they would threaten to flog me" – [Lina]

Participants also added that teachers' poor understanding of the biological implications of albinism and lack of support predisposed them to being punished unfairly. Nori recounts:

“I didn’t have the support in terms of – you know- I have a sight problem like visual impairment; I hardly see what is written on the board. Before my teachers actually detected that it is due to my albinism they did not understand that it’s not me not wanting to participate – like I don’t write in class because I can’t see what is written; they think that I’m just lazy to write – it’s just that I don’t see what is written. One day, my teacher saw I was not copying notes. She asked me why and when I couldn’t give her an answer, she caned me badly – this happened a lot of times” - [Nori]

Wales provides another example in consonance with Nori’s. Wales’ story also indicates that teachers contributed to his bullying experiences. Wales attended a boarding secondary school where he was expected to join other students for environmental sanitation during which time he developed skin lesions as a result of exposure to sunshine. At other times, to punish him for not wanting to work under the sunshine, teachers and senior students would designate Wales to a more distasteful chore of washing the school latrines:

“Some of the issues I had going back to secondary school where I will tell [the teachers] that I’m not supposed to be outside under the sun. In Africa, when you are in school, you need to cut grass and do some manual work [as a form of environmental sanitation]. Some people felt I was using it as an excuse and I had to be in the sun. So some of the skin lesions that I have were as a result of people in primary and secondary school refusing the fact that I wasn’t supposed to be in the sun especially during the day. The seniors would think that I was trying to dodge and the teachers would also agree with them because they were completely ignorant of that fact. So [sometimes] I was now given that [toilet] duty as a sort

of like punishment like “Okay. You don’t want to work out in the sun, so you need to go and wash those latrines” - [Wales]

In this study, participants identified their visual impairment as the most significant risk factor for poor school performance. For example, Wales articulately explained:

“I believe that my ability of not seeing the blackboard in primary school, slightly affected maybe things like spelling, things like pronunciations – generally knowledge like that in English [Language]. So even until now, I have difficulty spelling very simple things – probably because of that impairment I had when I was in primary school” - [Wales]

Similarly, other participants’ excerpts resonate the same pattern of poor school performance due to visual impairment:

“In my primary school, I had issues with my sight. Seeing the board was a bit difficult for me and I was repeating classes, it now delayed my primary school to the extent that those that we started together they’ve gone to secondary school [and] I was still there. It was not easy – I struggled and managed and came out of primary school” - [Uma]

“I start my primary school; when they write for board, I’m not seeing. I’m missing the spelling of what I’m writing – the words won’t be complete; so it made me low for my education” - [Besu]

‘My primary school was a little bit difficult because then, I was having eye problems. It was very difficult to pass exams - I can’t lie’ - [Ella]

More specifically however, a number of participants recall that their poor school performance was particularly on subjects like mathematics and biology because of aspects such as identifying numbers of similar shapes and specimen drawing:

Nori's story is typical of this:

"I have a sight problem like visual impairment; I hardly see what is written on the board. I had a serious problem with mathematics because I never passed mathematics because most of the time in maths when I see a 5 I think it's an 8; when I see a 3, I think it's an 8; and I keep making those mistakes in exams. Another was biology: there was an exam that they set for us, and we were to identify a specimen under the microscope and to be honest, I looked through the screen like three times and I did not see anything. But my other course mates will go and identify – that was even enough to make me different from them. I hardly can keep a straight line when I'm drawing things because of my sight. Because we have what is called nystagmus, you see the eyeballs are shaking, we can't actually focus on one object" - [Nori]

Nori's story also implies that her inability to cope with mathematics and biology further heightened her sense of being different from her classmates. Nori's difficulties with mathematics are similar to those of other participants as they stated:

"In school, my eyes really disturbed me because I can't see the black board very clear. There were some things which they would write on the board that I was not able to see it. So, I failed my mathematics and some other subjects but mostly mathematics" - [Fedizy]

“...But in terms of maths, I don’t copy when they are teaching. I don’t stress myself because I can’t see the numbers” - [Flexzy]

“When I was in primary school, I did not use to see clearly even when I move closer to the blackboard. Sometimes when I want to read a book, tears would be coming out from my eyes and because of that I could not understand maths...even until now” - [Lina]

The key points that emerged from these properties are: participants’ school experiences were characterised with unwanted attention from peers, peer-provocation and torment; teachers being complicit in the bullying of participants, and poor understanding of albinism and the consequent lack of support from the teachers. These experiences together with their visual impairment restricted them from full participation in learning, thereby, causing poor school performance.

Having identified these processes, it became necessary to explore the consequences of disadvantaging schooling experiences that can potentially compromise the social wellbeing and academic outcomes for children with albinism. The reason being that these findings may be crucial to inform the appropriation of holistic interventions by policy-makers in the education sector. The consequences of realising being different at school and associated experiences as narrated by the participants include interpreted descriptions of truancy, depression, self-exclusion, questioning self-identity, lack of self-confidence, self-hate, low self-esteem, and timidity, all of which have a negative impact on their wellbeing.

Lina’s story provides an example of truancy as a consequence of poor schooling experiences:

“Sometimes, I would skip classes and won’t go to school to avoid that boy. When it’s time for school, I would leave home under the impression that I’m heading to

school, but would end up hiding somewhere instead. I would dress up for school and go stay at my friend's until past 10" - [Lina]

In Uma's case, her story indicated that she developed timidity as a result of negative schooling experiences:

"So, I was timid that...you know when you are in a place that you can't talk. Everything made me timid and shy. I was not bold to speak out, I was not bold. So, I was timid that I will now be crying telling God that is it because I'm an albino? Why will I continue like this?" - [Uma]

For Fedizy and Flexzy, their narratives imply that the consequences of realising being different manifested as self-exclusion:

"It affects me so bad. I will sit lonely, and start crying and that's why I don't socialise much because I'm scared not to be embarrassed" - [Fedizy]

"At times, I decide not to make friends with others, not to associate with other people" - [Flexzy]

Cool Baby stated that she experienced self-shame and depression:

"I was always ashamed of myself. All of these made me withdraw and isolate myself from people. Whenever I felt depressed, I would stay quiet and keep to myself. I kept my depression to myself" – [Cool baby]

Besu's recollection bears resemblance with that of Cool Baby as she states:

“I will look at myself [and ask] “Why God make me only me be albino and see how others they are black, they are abusing me?” So I will be crying. So, I will be worried about [it] and be thinking and be crying” - [Besu]

Ella admitted struggling with low self-esteem because she hated being a PWA:

“At a point, I hated being an albino. I was losing my self-esteem as a child” - [Ella]

In Nori’s case, it was the lack of self-confidence which she still struggles with as an adult:

“Yes, I was conscious about my albinism. You keep losing your confidence, and it did happen to me. There are some instances I’ve failed to be more articulate because I didn’t want people to just notice that I’m even there. I’m not really quick in making friends - I would want to say it is because of the albinism – I don’t really make friends easily” - [Nori]

Data revealed that *being different* is a continuum of realities given that participants’ experiences in childhood were sustained through their teenage years in adolescence on to adulthood. At about the ages of eighteen and twenty, the majority of participants had managed to complete secondary education. For many of them, the next life decision was to secure a means of employment or enrol in apprenticeship training. The majority of them were resigned to these options for one or more of the following reasons: (i) poor grades because of negative schooling and learning experiences, thus, rendering them ineligible for admission into tertiary institutions; (ii) loss of interest in higher education because of poor learning experiences in primary and secondary school; (iii) unavailability of funds for tertiary education. Only a few participants such as Ella, Chojo, Nori and Wales proceeded to pursue tertiary education and thereafter, started seeking employment. Collectively, their experiences

at the various tertiary institutions they attended were rife with recollections of lack of support from lecturers for disability assistance and difficulties to write examinations in similar terms as when they were children. Regardless of the level of educational achievement, the two themes that shaped participants' experiences as they advanced in age into adults are experiences that pertain to social and romantic relationships and employment.

The following sections present participants' experiences within the context of adulthood and draw on how these experiences shaped their lives as PWA in Nigeria. These experiences position *being different* as a continuum even though the realities of *being different* manifested in varying terms different from when participants were younger.

6.4 Suffering double tragedy

For participants, the summary of their experiences of being an adult PWA can be conceptualised as '*Suffering double tragedy*'.

*“Being a woman in Africa is a disability. So imagine you being a lady and then, being a lady with albinism: **that’s a double tragedy for you in Africa**, in fact for all persons with albinism in Africa” – [Nori]*

In adulthood, *being different* manifests in the following contexts:

- Working environment
- Social life
- Romantic relationship experiences
- Social wellbeing status

Even though these contexts appear distinct, it occurred that the processes underlying participants' experiences are both overlapping and crosscutting. For example, the working environment is in itself a social environment where social interactions occur. Thus, it is

plausible to infer that the working environment constitutes participants' social life. As the findings reveal, these social interactions shape the nature of social experiences and wellbeing outcomes for participants.

6.4.1 Experiencing exclusion from employment opportunities

It emerged from the data that one of the major challenges of an adult PWA revolves around the pursuit of employment opportunities to support their livelihood. Based on this premise, the excerpts presented to support this property will include participants' job seeking experiences in the working environment.

Data revealed that most participants in this study felt that the working environment in Nigeria is structured to be inaccessible to PWA. Furthermore, participants who are fortunate to be in any form of employment feel marginalised by their work colleagues due to their physical appearance. For example, Chojo believes she was disadvantaged from a job opportunity because of her skin colour:

"I went for [a job] interview with my cousin; we now went for practicals. I did very well, but they did not take me because of the [my] colour - they didn't care. I'm not working now; I'm not doing anything for now" - [Chojo]

Another participant, Cool Baby, believes that she was rejected from employment due to her 'skin colour':

"Since I got to Abuja in 2010, I've been looking for a job to no avail. Even when people helped me to secure an interview, once I get there and they see my skin colour, they reject me. And I'm still passing through this condition even until today" - [Cool baby]

Cool Baby narrates an incident to support her claim:

“There was a time they needed an individual in Abuja to be the ward coordinator [for my local government]. The Councillor of our ward nominated me for the position and forwarded my name and contact details to the chairman of the nominating committee. I went to see the chairman at his office, and the moment he saw me, he said I was not qualified for the position. I believe it was my skin colour. There are lots of things that I deserved but didn’t get because of my skin colour” - [Cool Baby]

Fedizy once worked as a store assistant in her aunt’s shop. She believes that her physical appearance deterred potential customers from patronising the business. The excerpt below shows that societal attitudes toward albinism are evidently disadvantageous to the livelihood of PWA:

“I once worked as a sales girl. Some [customers] will come; at the entrance on seeing me, they will stop and turn back. I know that it’s just because of me without being told – I know”.

In the excerpt below, Fedizy describes several job-seeking incidents whereby she believes she was disadvantaged by her physical appearance and eyesight as a PWA:

“Like recently, I was looking for job – anywhere I go to, they will give me one complain or the other - they will just be turning me around. The second to the last place I went to, the man said he would have employed me, but it’s just because of my eyesight because the written documents are tiny – that he can’t make it bold just because of me. I went to another place yesterday again; they told the man that “there’s a lady outside looking for you”; he said “who’s

that?” they said “she’s an albino” He said “what will he use albino to do in his organisation?” That they should tell me that he’s busy. I shed tears yesterday, and I went back home” - [Fedizy]

Eki, after completing her General Certificate of Secondary Education examinations (GCSEs), enrolled in apprenticeship training to become a seamstress. In her excerpt below, she implies that visual impairment limited her functional ability in the workplace:

“... after writing the exam, my sister said I should go and learn fashion and designing. I was going to that fashion and designing shop. What made me change my mind was that by the time I want to put the thread into the needle, it’s very tiny – you understand? Along the line I [had to] stop” - [Eki]

Eki goes further to narrate her experience of being disadvantaged from employment on the basis of her visual impairment:

“Sometime in 2001, I went to [the] police college to join the force at least if it is the cooking aspect [police chef] or tailor aspect [police seamstress] so that I can help myself in life. [The director said] that they don’t receive people living with [albinism] - they are not allowed to work in Nigerian [armed and paramilitary] forces. The man said albinos cannot see from afar; that is why anything pertaining the armed forces in Nigeria, they don’t admit them [albinos] because they don’t see from a far distance” – [Eki]

In another incident, Eki describes a job-seeking experience when she believed she was discriminated from employment because of her physical appearance as a PWA:

“I went for a house-keeper job interview. The [hiring] manager walked in - the way she was just staring at me. So, she entered the office. I don’t know what they discussed. After a while, the guy now came out and said they’ve cancelled the interview. But to me, the truth of the matter is that the woman didn’t like the person she saw. That is one of the discrimination we are talking about. I don’t know if you understand? You see your fellow human being as if she’s nothing”- [Eki]

For some participants, working experiences were characterised by social stigma and exclusion from active work participation. For example, Lina was compelled to leave her job as an office assistant after the occurrence of an incident that she believed to be a stigma due to her visual impairment:

“I started work in the University of Nigeria. The man [my supervisor] will just call me that “Please go and bring so and so thing for me in the other office”. Maybe if I went there to go and look for that file, I didn’t see it, he will just come - he will be shouting on my name that “You! And you said you want to work and you can’t see. Please stop coming to this place” I will say “God why?!” I will just start crying. “Why won’t I cry? See how this man is shouting on me because of...” After a while, I just decided to leave the job for them [without making a fuss]” - [Lina]

Lina enrolled as a hairdresser apprentice. However, Lina’s visual impairment disadvantaged her from active work participation in that customers disallowed her from making their hair because they feared she would accidentally prick them with the needle. Lina believed that customers used her visual impairment as an excuse to cover their prejudice against her physical appearance of being different as a PWA:

“So all this fixing somebody’s hair - I started that work. Customers don’t use to allow me to touch their hair, you understand? Any customer that comes to my shop - my madam’s shop, they will say “Please, if it is that albino girl, I don’t want her to do anything for me. I don’t want her to prick me with the needle”. They [customers] will say no - they don’t want me to touch their hair because I will prick them with the needle; even to wash their hair, they won’t allow me to wash their hair. All my mates will be there doing hair and making money. After my graduation, I left that place” - [Lina]

Data also revealed evidence to suggest that being highly educated does not exempt PWA from negative experiences in the working environment. For example, Nori who has a postgraduate qualification shared her job-seeking experiences of being turned down by potential employers because of physical appearance in a similar representation as other participants:

“I’ve had so many applications I’ve put in the past- [I] look good on paper but when they see [me], especially in Nigeria, they like “We will get back to you” and I’ll never hear of that again. And some jobs that will say put your passport [photograph]; that one from the onset, I know I am not getting a call. So yes, I have had instances like that. It took me a while to get a job¹³” - [Nori]

¹³ As at the time of completing this thesis, Nori had started working at an international organisation for cultural relations and educational opportunities in Abuja. She was employed on merit having successfully passed the required recruitment assessments.

In another dimension to negative experiences in the working environment, Wales draws on experiences when his competence as a medical doctor was questioned due to being different as a PWA:

“At work, some people look at me and like “Is this guy competent to do this thing?” - [Wales]

Wales explained that there were times when people believed that he has supernatural powers because of being different as a PWA. This supposition represents one of the many social constructions of albinism with which the Nigerian society use to stigmatise PWA.

“When they see [me], they believe that maybe I have certain supernatural powers or [I’m] from the occult. I actually attended to a patient that was bipolar manic. When he saw me, he knelt down and he said he wanted to worship me because I’m a god – because of the way I look” – [Wales]

In the case of Besu who works as an office cleaner, her experiences in the work place highlight stigmatisation and social isolation. Even though she did not use the word ‘*stigma*’, the excerpts from her story describe indications of marginalisation and social stigma because of the negative attitude by people in her work environment:

“I got a job as an office cleaner. My colleagues who are black would always gossip about me that “Who will marry an albino?” Even the office workers do not want to have anything to do with me. I hear them say things like “an albino is scary”. Whenever I hear these things, I get home and cry. I look at myself and ask God “Why have you made me an albino for these black people to abuse?” I always feel distressed and worried”. - [Besu]

Finishing her statement, Besu expressed dissatisfaction at what she believes to be an injustice in the form of discrimination and exclusion of PWA from public service employment:

“Like now, we albinos if we are struggling to look for work, for jobs like: police, civil defence, they will not carry us because we are albino. So I don’t agree like that” – [Besu spoke in Pidgin English]

“For instance, when people with albinism go looking for work in the police force, or civil defence, they won’t recruit us because we are people with albinism. I do not think it is fair” – [The English Language translation of Besu’s excerpt]

Even though participants did not actually use the words ‘exclusion’, ‘discrimination’, ‘stigma’ and, ‘injustice’, the narratives of their experiences were replete with phrases such as *“they did not take me because of [my] colour”*; *“...lots of things I deserved but didn’t get because of my skin colour”*; *“they don’t receive people living with albinism”*; *“they won’t allow me wash their hair”*; *“...do not want to have anything to do with me”*; and *“they will just be turning me around...he would have employed me but it’s just because of my eyesight”* to describe various incidents of job seeking and employment experiences in the working environment. These phrases could be interpreted as indications of social stigma, discrimination, and injustices because of the participants’ skin appearance and poor vision.

Participant’s stories were used to trace the underlying reasons for these working and social experiences to the perceptions that participants believe the Nigerian society holds about PWA. Participants believe that society has ascribed labels to PWA and these labels influence how people perceive and treat them, which often result in adverse consequences to their social wellbeing. For example, Besu described her belief of how the Nigerian society sees her in terms of being perceived as weak, fragile and scary. Here is what she said:

“I can see all those black people, they will say “Who will near albino? “Me I’m fearing albino”. They say they see us like this that our skin is not strong and for them to nearing the skin, touch the skin, they are fearing” - [Besu; verbatim transcription in Pidgin English]

“I look at the people around me and hear the things they say about people with albinism. I hear them say things like “an albino is scary”. Some people think our skin is not strong and that is why they fear coming near us” [Besu’s excerpt in direct English Language translation]

Wales sums up what he believes to be people’s opinion of him and by extension, of PWA in general. His excerpt highlights labels for PWA as weak and fragile; lazy and blind.

‘[I] heard misconceptions about people saying the reason why [I] don’t want to go out in the sun is because [I am] lazy and it’s not because [I] really should not have contact with the sun. You know there is a general perception that albinos are weak, breakable; they have the tendency to be lazy; they can’t do work...maybe [I’m] in the car driving, some people will say “Ha! Move away from the road, this guy cannot see; this guy is blind” - [Wales]

Other participants with similar opinions on societal perception of PWA as lazy and blind are as follows:

“They think that I’m just lazy” - [Nori]

“...some Nigerians look at us as if we are not human being[s] which is very very wrong. Remember that I told you I was rejected for work because the man said albinos cannot see from afar...that we are blind” - [Eki]

“People would mock and tease me saying “all albinos don’t see clearly at daytime” - [Cool baby]

6.4.2 Double tragedy as it relates to romantic relationships

These social constructions of albinism may provide a basis to explain the origins and implications of *being different* in terms of relationships. Indeed, one of the aspects of female participants’ social lives that is most affected by their *being different* is in forming and maintaining romantic relationships. Participants reported numerous incidents where their difficulties in making and keeping relationships were attributable to their *being different*. Participants believe that their negative relationship experiences are a consequence of their albinism, which to a significant extent is because of how society constructs albinism. Some participants expressed concerns about how Nigerian men perceive women with albinism and how this perception defines romantic relationship not only for women with albinism, but for PWA in general.

For example, Chojo stated an incident when she overheard a conversation in which someone attempted to discourage her former partner from marrying her because PWA are perceived as weak individuals:

“...people outside they said “Why you wan marry albino? Dem body no strong” - [Chojo in pidgin English]

‘His friend asked him “Why do you want to marry an albino? Albino bodies are not strong” [Chojo’s excerpt in English Language translation]

As a way of example, Nori attributes her difficulty in forming social relationships to albinism.

“In terms of friends, all my life, I’ve had very few friends. I’m not really quick [at] making friends. I would want to say it is because of the albinism because of the fear of being rejected– I don’t really make friends easily” - [Nori]

She goes further to elaborate on how societal perception of her impacts her chances of romantic relationships:

“I am still battling with in terms of how persons in the society perceive me as a lady with albinism. They think [I] might not be able to do what a “normal lady” should be doing in the home – that’s one. Two – persons with albinism are perceived as people with low confidence which is 95% true. When it comes to relationship with the opposite sex, when I did not have as growing up probably people coming around kind or wanting to have a relationship with me...it is a serious issue I wish somebody can come up with a strategy” - [Nori]

Similarly, Cool Baby also attributes her unsuccessful romantic relationship experiences to her albinism which led to an eventual loss of interest in intimate relationships:

“I clocked twenty-one years before I started dating. All my relationships have been short-lived; I’ve been used, disgraced, disrespected and rejected because I am an albino. I’ve also had to tolerate a great deal of unkindness from the family of the men I have dated. This has made it difficult for me to sustain a relationship even until now. I currently am not interested in dating anyone” - [Cool baby]

Telling her story, Fedizy describes deception and rejection from men which led to an eventual loss of interest to foster a romantic relationship. As a result of poor relationship experiences, Fedizy struggles with feelings of inferiority which often make her question her identity as a PWA:

“The one I’m dating now is a cheater. I later found out that he’s cheating on me. I even heard him telling his friend that I’m an albino; that do I think he will marry me? I don’t want to continue with the affair again. I’ve had one before him– he was always mocking me at the back. He later told me that he doesn’t want me again that I should go. He now started dating my girlfriend – a black one. It affected me in many ways because I started feeling inferior; I felt as if...at times, I will say “Why did God even create me this way?” Me I can’t even predict who is real and who is not real. So, I don’t pay attention to them [men] like that anymore” - [Fedizy]

Similarly, Eki recalled her experiences of being deceived by married men who already had families:

“There was a time I had a friend that [was] coming for my hand in marriage. He didn’t tell me before [that] he’s married with three kids. As for me, I don’t want to become a second wife.

I [had] a friend again; [he] told me he had no wife, no children. I went to his place; he instructed me to wait for him at his neighbour’s. The neighbour called one of his son’s name. [When he arrived] I confronted him “Why did you lie to me? You said you are not married, but you are married with three kids!” He said it’s because of the love he has for me - that is why”. I find it difficult to believe men because I feel like they love telling lies” - [Eki]

Continuing her story, Eki drew on an experience when a potential suitor withdrew interest to marry her because she is a PWA:

“We met on the internet through online calls. This [friendship] continued for one year plus - we were always discussing [over] the phone; he can call me more than 20 times in a day. One day, he asked me “Are you fair or black [skinned]? I said “I’m [an] albino. If you are interested you should come down and see my people” The next day, he told me that his pastor said he should not marry yet. That was how we stopped communicating until now. Let me just say what he’s expecting that is not what he saw; let me conclude that way” – [Eki]

Another participant, Besu shared her relationship experiences of being deceived by a man. Besu is a lowly paid office cleaner; she remains unmarried and continues to cater to the needs of two children as a single parent:

“A man saw me that he like me. I explained to him “You see that I’m [an] albino; and you see how I be. I don’t want anybody that [already has] a wife and I don’t want anything that will stress me again; I want person that will help me. [he told me] that he never marry; that me I should not worry...deceiving me like that- that he will go and see my parents– I come take in for him, come born baby girl for him. He just reach my place one time. Then after I born the baby girl, he now explain to me that “Please, I should not vex o – he have wife with four children, that they are in the village”. We are manage like that; I still have another boy for him – baby boy. But from the boy, he disappoint me totally [and] abandon us without help me again. He just abandon me without taking care of the children. [He] don’t take care of me. It’s only me where I’m manage doing cleaners that I’m cope for all those things” - [Besu; verbatim transcription in Pidgin English]

“I met a man who said he liked me. I explained to him that I am an albino and I do not want a man who is married. I told him I needed a supportive husband who would help reduce the stress I already face as an albino. He told me he was not married and promised to help me. He kept deceiving me that he would go see my parents for marriage rites. He kept deceiving me until I got pregnant for him. After giving birth to my daughter, he visited me once and confessed that he is married with four children. I kept managing the relationship with me and had a baby boy. After the birth of my son, he abandoned us totally. He stopped taking care of the children and me. I sustain my children on poor wages from cleaning jobs” - [Besu’s excerpt in literal English Language translation]

All the participants who spoke of negative relationship experiences were women. Their excerpts reveal the difficulties experienced by women with albinism in Nigeria, as they continue to encounter multiple layers of injustices, social stigma, rejection, deception, abuse and unfairly ascribed social identity, all of which reduce chances to form and sustain good romantic relationships.

Nevertheless, data from a male participant suggest that men with albinism are also likely to experience challenges with relationship although with less complexity than women with albinism. In the case of Wales, even though he did not describe any relationship experience in particular, he acknowledged the difficulties he encountered whenever he attempted an intimate relationship.

“I was a bit awkward socially because of the stigma, the discrimination. When [I started] picking interests in women. I had extreme difficulty. Throughout medical school until I finished, I never had a girlfriend. It was very difficult; when I tried

once or twice, there was always that rejection. It now sort of made me feel “will I ever find a life partner?” - [Wales]

6.4.3 Being taken advantage of as a female with albinism

A couple of female participants shared experiences of sexual abuse which have made them to lose trust in men and the desire to pursue romantic relationships.

Ella's excerpt below strengthens the claim made by other participants that women with albinism in Nigeria may be targeted for sexual exploitation. Ella's experience of sexual abuse resulted in adverse wellbeing outcomes which further heightens her conceptualisation of social stigma.

“The aspect I have a little bit of challenge is relationship wise. Men who go into a relationship with me often believe they deserve thanks and reverence. Some men - they want to have [me] because [I am] an albino - to taste me – to take advantage of [me]. One of them said he liked me, that he would help me. But he deceived me and forced himself on me. I got pregnant. I struggled with [an] inferiority complex, frustration in school, dropping out of school, depression and suicidal tendencies due to stigma and discrimination” - [Ella]

In addition, Uma's story corroborates negative intimate relationship experiences of deception, and eventual loss of desire to pursue intimate relationships. Her narrative contributes to the notion that female PWA may be targets for sexual exploitation. Uma said:

“Relationship with men was not good, I was being jilted on. I have been unfortunate with men. Maybe I'm being taken advantage of because of I'm an albino. Other men that will come it's as if they just want to have fun and just go, that was what I was getting from them”

Uma recalled an experience of sexual abuse which led her to conclude that she was being sexually exploited because of being a PWA:

“This one came [pretending to be] holy, living a pretentious life. We met in a vehicle - that’s how he talked to me [and] we became friends. Whenever he comes to Abuja, he visits me - we talk. We were going out [dating]. One weekend, he was at my place. And all of a sudden I was lured again – even though I did not want to, he had his way. I was being used again. And it resulted to pregnancy. He was being so sincere so I didn’t know that he could do me like that. Till today I’m speaking I have not seen him and I’ve not heard from him. I only have his phone (number) that I call and he doesn’t pick up. Relationship with men - none for now. I decided to zero men from my mind” – [Uma]

For some participants, even though they have not experienced sexual abuse, they still believe that women with albinism are targets for sexual exploitation. Lina, Fedizy and Eki stated respectively:

“You know Abuja men; they like to deceive people. They just want to see somebody’s body, you understand...let me just taste and see” - [Lina]

“Men just want to play and go” – [Fedizy]

“Ah! Is it that this colour is making them to now [pretend being interested?]. They say they want to have a feel of how an albino lady will be” That’s what I just have in mind that that’s what they are doing - [Eki]

6.4.4 Inhibiting social wellbeing outcomes

According to the participants in this study, their life experiences explored so far have implications on their social wellbeing outcomes. In their stories, participants constructed their social wellbeing in terms of feelings and states of mind that continue to inhibit their full participation in the society.

For example, in the excerpt below, Lina used phrases such as “*I...decide not to talk with anybody*” and her repetitive reference to ‘*feeling bad*’ to suggest feelings of internalised stigma, depression, inferiority and intentional disconnection from social interactions:

“Sometimes I would just wake and will decide not to talk with anybody... I will just be on my own. I feel bad. On the day of my girlfriend’s wedding, I was not happy because I was the only fair-skinned person in that place; everyone else was black, so I was feeling bad. Sometimes when I am going to town with my friends, I would look at myself and start feeling bad” - [Lina]

In similarity with Lina’s story, Cool Baby admits to feelings of internalised stigma and intentional withdrawal from social gathering because of social stigma:

“...but I am always ashamed of myself. I do not want to go out or partake in any communal functions. Even on rare occasions when I attempt engaging in any communal activities, people would mock and tease me. All of these made me withdraw and isolate myself from people” – [Cool baby]

In the next excerpt, Fedizy attributes her intentional withdrawal from social gatherings to anticipated social stigma:

“I don’t socialise much because I’m scared not to be embarrassed. I don’t cope well - it’s really hard for me. Instead of going out to face challenges, I won’t go. I will just be at home, reading – just to while away time” – [Fedizy]

In the excerpt above, Fedizy’s use of a phrase such as *“I don’t cope well- it’s really hard for me”* gives a sense of how her life experiences continue to limit her social functionality. She narrated an incident of being stigmatised while attempting to access healthcare services:

“I’m not confident at times to go to the hospital because I think within my own self that the doctor won’t attend to me. If it’s a female doctor, some of them do mock me. So, I don’t love going to the hospital due to their behaviour. One time, I went there [the hospital] - it was concerning my eyes problem as the eyesight was becoming too much for me, it was unbearable. I saw a lady nurse. So, I was asking about the doctor. She said “What is an albino like me doing here?” I just felt embarrassed because many people were there”- [Fedizy]

Nori reported feelings of inferiority and consequential adverse effects on her chances to pursue life opportunities.

“You can’t really root out low self-confidence. There are some instances I’ve failed to be more articulate because I didn’t want people to just notice that I’m even there. Some people believe in what I can do, but I don’t believe in what I can do. For me, that is a cankerworm that should be expunged from the life of a person. I think I’ve missed out a bit of opportunity in life because of that. It has limited my achievement I will say. Yes, I think I’ve lost a bit of opportunity” - [Nori]

Particular focus on “...*I didn’t want people to just notice that I’m even there. Some people believe in what I can do, but I don’t believe in what I can do*” is indicative of internalised stigma. Nori further describes the difficulties of accessing healthcare services to maintain her health and wellbeing status. Her excerpt below laments the failures of the healthcare system to cater to the needs of the visually impaired:

“Speaking from the Nigerian context, accessing health care in Nigeria is already a minus. I go to a big hospital, and I need to identify departments and the signs they are writing, I cannot see it because the outlay in the hospital is not disability-friendly – that where I have challenges. The major one is accessing healthcare for visual impairment - It’s going to cost you a lot of money – even the government clinics are even expensive. As we are speaking, I’ve not been wearing glasses for almost seven months, and I’m not finding it funny and there’s no provision for the visually impaired” – [Nori]

As for Wales, even though he enjoys socialising, he acknowledges his struggle with social stigma and the avoidance of social gatherings as a consequence:

“At times I go to clubs to drink and all of that. I have bad days, and I have good days. I won’t say I’ve overcome – it’s a work in progress. In the market, people calling [me] names; cat-calls and all of that - it gets to [me]. I avoid large social gatherings’ - [Wales]

While some participants have disclosed negative social wellbeing outcomes, there are a few participants whose stories offered some variation in terms of positive outcomes. For example, Besu conceptualises her social wellbeing as being mediated by people’s positive attitude and disposition towards her within her residential neighbourhood. Besu’s excerpt below implies

that her neighbours respect her because of her children's normal skin colour and physical appearance. This gives her a sense of pride that further improves her social wellbeing:

“The area I’m living now, I have respect because of the children. Because what the black people have, I [also] have; they have black children and God gave me the black children [as well]. So, I have respect for the area I’m living. They are relating with me very well. I am happy” – [Besu]

Similarly, Eki attributes her social wellbeing to people's positive attitude and disposition towards her in her neighbourhood. Her excerpt implies feelings of self-confidence and high self-esteem:

“My neighbours are nice to me. I’m full of myself even if I don’t have anything. And there’s something I used to tell myself always when I stand in front and look at myself in the mirror, I say “Eki you are beautiful”. Nobody should talk to me out of pity; don’t come to me because you are pitying me – no! Anything [out of] pity, I don’t like it. Instead of you sympathising with me, show me what to do that will help me. I do not make myself cheap for anybody”- [Eki]

In this theme, participants have constructed their social wellbeing as a derivative of their interaction with the society. For the majority of participants, these social interactions inhibit their sense of social participation, which consequently limit their involvement with other members of the society. Again, these life stories further strengthen the claims made in this study that society's perception of albinism is the factor underpinning *being different* as a continuum of realities that is sustained through all life stages of PWA in Nigeria.

6.5 Coping with ‘being different’

Drawing on the emerged theory of *being different*, participants reported various coping mechanisms they have adopted to build resilience to manage the realities of being PWA in Nigeria. These findings are particularly useful given their potential to complement prospective interventions for PWA at different life stages. Participants highlighted the following as means to cope and build resilience against the challenges and injustices that accompany being different.

- Coping with negative learning experiences
- Joining the Albino Foundation
- Inuring self and retaliating name-calling
- Having faith and engaging in church activities
- Relying on family for support

6.5.1 Coping with negative learning experiences

The findings revealed that participants had begun to adopt certain coping mechanisms right from childhood when the disadvantages of the schooling environment excluded them from fully participating in classroom learning.

Participants’ narratives provided insight on how they were able to cope with schoolwork amidst the challenges posed by visual impairment, lack of support from teachers, the realisation of being different and its associated disadvantaging learning experiences. The data reveal that *borrowing notes from classmates to copy* was the general coping mechanism the participants adopted as a means to manage schoolwork. This is exemplified in the excerpts below:

“I had a friend who was very nice to me. I used to collect [borrow] her exercise book to copy” - [Eki]

“I’ll stay at the back and copy, or I’ll beg others that have [lesson] notes to give me. So when I beg, some will give, some will not” - [Uma]

“Rather than suffer myself, I would wait for them to finish and either move closer to the board to write my notes or borrow from a friend and complete the notes at home” - [Cool baby]

Participants Wales, Flexzy and Nori claimed that they developed good listening skills to complement having to borrow lesson notes from classmates:

“Since I’m not good with my vision, I try with my ears. After listening, I do collect notes from other students and copy” - [Flexzy]

“I imagine what the teacher is writing – at least, it developed my power for imagination...I was just writing what I heard. Sometimes, after copying on the blackboard, my classmates also gave me the notes to copy. Yes, it did assist me’ - [Nori]

In addition to borrowing notes from classmates, Wales’ mechanism for coping with the challenges of negative learning experiences was to improve his academic abilities:

“...after the class, I will now be begging my fellow classmates for their [lesson] notes so that I can copy. So after a while, I was very adept at writing very fast from what people are saying. So, I was always able to – even for someone that speaks very fast; I was able to adapt that skill of writing what they were saying rather than writing what is on the board.

...because I was a bit awkward socially because of the stigma and the discrimination, so I pumped most of my energy in academics. I focused on my

books- on my academics. That's when I began to realise that if you are actually smart in school, others will now be coming to you to teach [them] and that increases your self-esteem in that way" - [Wales]

Contrary to the other incidents where borrowing notes was an adopted coping mechanism, there were two participants whose stories revealed some variations in the pattern of negotiation. For example, Lina brokered a business deal with one of her classmates such that she paid said classmate to help her complete lesson notes. At other times when Lina did not have money, she exchanged food with her classmate for the service.

"When I got to primary six, I was still facing the same challenge with my eyes – I couldn't see in class. I had to cooperate with one of my classmates to help me write my notes. The girl would often ask me for money before writing the notes for me; sometimes five hundred naira, sometimes two hundred naira. Sometimes if we cook, I will just dish the food and bring for her. I will say "Esther, I have brought food for you. Just help me to write", then she'll help me write" - [Lina]

In Ella's case, she depended on being assisted by her sister and a friend to help her complete her lesson notes and homework:

"Sometimes, my immediate younger sister would help me out to do my homework. Sometimes, on one of my friends, NG - I can still remember her – she would still help me out" - [Ella]

6.5.2 Joining the Albino Foundation

The Albino Foundation (TAF) is a non-governmental organisation that champions disability rights and inclusion for PWA in Nigeria. In their stories, participants described how being members of TAF has helped them cope with being PWA.

For Besu, she derives a sense of belonging from attending monthly meetings with other TAF members:

“As I joined the Foundation, it’s giving me more joys as we albinos are gathering for the meetings. If we join like that, I’m not feeling like it’s only me that is albino. During the meetings, we discussing with ourselves, it gives me more joy – it’s not like before that I’m feeling only me albino” - [Besu verbatim in broken English]

As for Uma, TAF has empowered her with understanding and management of albinism:

“I gained some knowledge from the [Albino] Foundation that we should take care of ourselves, be bold about ourselves and to cover up when I’m going under the sun. I’ve understand now that I’m not supposed to stay under the sun and I understand that it’s in the gene now” - [Uma]

Chojo and Eki have acquired more knowledge on how to manage dermatological implications of albinism by being members of TAF:

“The experience I have since I joined the Foundation is [to avoid] sun. Before I didn’t know that we have problems with sun and truly, since I stopped entering under the sun – I can see the difference” - [Chojo]

“Since I started coming to the foundation, I never regret my coming to the foundation. The only care we can do is avoid sun from 10 am to 3 pm which I’m doing it. I was coming to the Foundation, from there they said albino is not allowed to wear short sleeve that short sleeve is not good for us. As albinos, we

should be going with umbrella, and almost all the time, we should be on hat and I've been doing that from time to time” - [Eki]

With the help of TAF, Cool Baby copes better with self-acceptance:

“I am glad I joined The Albino Foundation because it has helped me to accept myself and my brother who is also an albino because I was always ashamed of him - I don't know why. But since I joined the Foundation, my understanding and acceptance of albinism has increased. As a matter of fact, each time I visit the village [where my brother still lives], I always encourage him to go out with me”
- [Cool baby]

6.5.3 Inuring self and retaliating to name-calling

For some participants, growing ‘thick skin’ and ignoring derogatory comments from the public has helped them cope with being PWA. ‘Inuring self to name-calling’ as a coping mechanism is supported by the following excerpts from participants’ narratives:

“Once in a while, I don't mind people having couple of laughs at my expense. You know when somebody is trying to discriminate or look down on you, and you don't give a damn, they will be like “What's up with this guy? This guy is supposed to be beneath me, so why does he still act as if we are the same?” -
[Wales]

“...right now, each time they call me [names] now, I just ignore them because I know it doesn't take anything away from me” - [Flexzy]

“At times, I will just do as if I don’t even hear what they are saying. And at times, when I’m even walking, even though they call me names, I will pretend as if I don’t hear” - [Fedizy]

“It’s becoming too normal to me that I can’t differentiate when people go out to discriminate, I don’t really recognise it; it does not really bother me any longer” - [Nori]

“But for now, I’m OK - no problem. Even though you like call me ‘oyinbo’, ‘afin’, anything, I don’t mind” - [Lina]

For a couple of participants, their coping mechanism includes immediate retaliation and reaction to derogatory comments. For example, Wales has become intolerant of discriminatory comments and attitude:

“... [but] people who I believe should know better and who are at an age that they should be matured and even older than me that show me discrimination, I’m very upfront and forceful towards them. I correct them immediately and I try and resolve the issue there and then - I challenge those things” - [Wales]

As for Chojo, she reacts to name-calling by retaliation:

“For me, if they call me name, I will give them name [back]. If they call me name, I will find name and give them and then, the name that I will give them they will not like it and people will join me and start calling them the name. Because if you dey shy, dey cool somehow, they will continue calling you. But if you they call you – you give them name and the name that you give them people are joining you to call them, they will stop. Nobody will call you names again” - [Chojo]

6.5.4 Having faith and engaging in church activities

In combination with other coping mechanisms, some participants adopted having faith in God and participating in church activities as a way to build resilience against the social consequences of having albinism.

For example, Nori described how seeking pastoral care and guidance enabled her to engage in church activities as a result of which she is able to cope:

“Presently, I’ve started a mentoring class. What I did was to seek out the help of a spiritual director; he’s a psychologist as well but he’s also a priest – a spiritual director who I normally go to see one-on-one to talk about these things. At a stage, he asked me “You’ve so much focused on your limitation and your weaknesses, what is it that you like doing?” And I told him I love singing. So he said “Go and sing. I think it will solve your problem” And it did! It really did solve the problem of self-confidence and self-esteem. I was in the choir – I started singing in the church choir. Before I knew it, I started noticing other talents; I can conduct, I can beat instruments, I can dance. There was so much that I was doing in the choir that people were like “you are everywhere”. And before I knew it, I was just focussing on getting more, you know, enhancing my abilities and I forgot about every other thing that is a weakness to me” - [Nori]

Other participants with similar coping mechanism are Lina and Uma as they stated:

“...like I’m a choir member. So any time I go to church, I would be feeling happy’ - [Lina]

“I am in the Redeemed Christian Church - in the choir. I just choose to serve and just be with God; I’ve been serving in my unit as the choir still in that same

church - that's how I've been and the church was supportive, they were helping me" - [Uma]

Other participants described how adopting faith in God is a way to cope with the challenges of being a PWA.

"I said "God, I'm not discouraged. You created me and you know the way you are going to sustain me in [on] this earth, so I'm not moved" - [Eki]

"I don't feel any of these things anymore because I have come to the realisation that all things bright and beautiful - My Lord God made them all. I didn't have a choice of skin colour from birth so if God saw a need to make me special, I have no choice than to rock my albinism in a decent way and be thankful" - [Ella]

"God has His reasons for making me an albino. I am convinced that He has a purpose for me" - [Cool baby]

"Be albino or anyway, God is with us" - [Besu in pidgin English]

"Either I am an albino or not, I believe God is with me" – [Besu's excerpt in English translation]

6.5.5 Relying on family for support

For some participants, family helps them cope with the challenges of being a PWA.

"I don't cope well - it's really hard for me. But they [my parents] will give me advice how not to listen to the black ones outside that are mocking me. It helped me a lot. Because it does not make me to think about those ones outside" - [Fedizy]

“I thank God for my very lovely and encouraging family that kept me going” -

[Ella]

In sum, participants’ descriptions of various coping mechanisms that have been explored in this category is an indication of their resilience as they continue to attempt to have a normal and respectable life in a society they believe has a poor understanding of albinism.

6.6 Consolidated reflection on findings

The contexts within which the realities of *being different* manifest itself in participants’ childhood and adulthood are as illustrated in Table 6. According to participants’ life stories, *being different* originated from three primary sources, namely: home environment, schooling settings, and working environment; all of which constitute the social environment.

For the participants, *being different* as a consciousness of personal and social status occurred in two processes. The first process was when the participants realised that they are different and the second process is when participants began to realise that *being different* places them at various realities of disadvantages. For each participant, the operationalisation of these processes depended on the origin of *being different*.

The home environment as the primary origin of *being different* was determined by participants’ *relationship with parents and siblings*. For all participants, the commonality of realising *being different* evident by skin colour and physical appearance began in the home. However, whether this process of realisation was well tolerated or otherwise depended on the level of acceptance and provision of support and love by parents, and by extension, siblings. It emerged from the findings that parents’ level of education might have influenced participants’ relationship with family members within the home environment to suggest that educated parents are more likely than uneducated parents to understand and manage albinism

and therefore provide a supportive home environment for the CWA. Participants whose parents are educated were able to embrace the awareness of *being different* but were not disadvantaged. In plain terms, realising *being different* from other family members in the home environment was not a negative experience, and there were no triggers of any adverse psychosocial tendencies. However, in the case of participants whose parents are not educated, the realisation of *being different* conveyed a negative sense of differentness in terms of inferiority to other family members. Participants implied that this occurred because their parents lacked adequate understanding and management of albinism. Indeed, for many participants in this study, the two processes of *being different* manifested fully in the home environment.

While this study was not designed to interview participants' parents and family members, participants provided information to understand why their parents could not manage albinism which further led to unavailability of support in the home environment. In their opinion, participants believed that in addition to not being educated, their parents' negative reactions to them as CWA were driven by society's perception of albinism as a harbinger of social embarrassment and ridicule within a Nigerian context. This was interpreted to mean that for parents with low or no education who have internalised society's perception of albinism, they regarded their children with albinism as a cause of shame and demotion of social status. If this is to be understood in this way, then it became evident that social stigma of albinism was able to permeate the home environment, influence familial relationship and shape the reality of life for children with albinism.

While the process of *being different* may have already been initiated within the home environment, participants began to learn the consequences of *being different* from the social experiences in their various social settings. It emerged from the finding that even though all

participants had negative social experiences, the level of adaptability differed. For example, in the case of participants who were already exposed to negative treatment and reactions from parents and siblings in the home environment, negative social experiences merely heightened the process of learning that *being different* places them at a disadvantage of social rejection and exclusion in the community. However, for participants who were fortunate to enjoy the privileges of a supportive home environment, the awareness of the disadvantages of *being different* did not occur until outside the home environment. Participants in this latter group learned that stepping out into the social environment presented them with an altogether unfamiliar reality of negative social experiences of exclusion from playgroups. All participants attributed their negative social experiences to the fact that children and other members of their social settings used society's perceptions of albinism as a tool to treat them negatively. The majority of participants believed that their peers must have internalised unfair beliefs about albinism and PWA as was passed on to them from parents. Again, it became evident from findings that social stigma of albinism was a significant contribution to participants' adverse experiences within the home environment as well as in social settings. It was noted that at this stage in participants' childhood, the only disadvantage of *being different* that participants were aware of is that their skin colour and physical appearance was used to disqualify them from participating in social events such as playgroups in the neighbourhood and birthday parties.

As participants progressed in their childhood, entry into the schooling environment presented them with the harsh realities of other disadvantages of *being different*. The findings established that schooling experiences had the potential to set a pattern of deprivations for the rest of participants' lives. In the first instance, it became clear that the schooling environment as a formal social institution comprised teachers and other children whose internalised perception of albinism and PWA reflected in their world view and in everyday interactions.

In this perspective, it can be argued that the social stigma of albinism manifests within the schooling environment. All participants experienced being bullied, taunted and name-called by peers in school because of their skin colour and physical appearance. Considering that negative treatment by peers was not an unfamiliar experience for participants as already observed in their social experiences, data proved that there was transference of experiences from social settings into the schooling environment.

In addition to being treated negatively by peers in school, the most profound disadvantage of *being different* that defined learning experiences for participants was their visual impairment. Inability to see the blackboard as a result of visual impairment meant that participants could not fully participate in classroom learning and were always behind in completing lesson notes. In addition to the lack of support from teachers which participants believed was particularly fuelled by society's perception of albinism, the chances for participants to attain achievements in life as adults were significantly reduced in their childhood because of the unavailability of learning materials adapted to be used by people with visual disability. Simply put, participants found themselves in a learning environment that was neither tolerant of their differentness nor configured to accommodate their visual disability, thus creating margins of inequality to access full learning participation at school. The end product of schooling experiences was that the majority of participants were unable to adequately access education and gain qualifications that would have enabled them to be eligible to pursue life opportunities.

As participants transitioned into adulthood, they developed various mechanisms to cope with societal unfairness; nonetheless, an inconsiderate society remains a threat to their attempts at building resilience. In participants' adulthood, *being different* manifests in the context of the working environment, social life and the ability to form romantic relationships. In like

manner as the schooling environment, working environment comprises other members of the society whose beliefs about albinism and PWA are evinced in their interactions with participants. Findings suggested that participants' inability to acquire marketable qualifications significantly limited the scope of job eligibility, thereby compelling the majority of participants to apply for lowly paid blue-collar and pink-collar jobs. Participants' attempts to gain employment were primarily frustrated by exclusion from recruitment on the basis of their skin colour and physical appearance. Participants believed that their exclusion from employment was driven by the stereotypes that the Nigerian society has attached to albinism and PWA.

Furthermore, in resemblance to schooling experiences, participants realised that visual impairment was used by the Nigerian society to deny them the opportunity of actively engaging with the working environment. For a few participants who are employed, workplace colleagues continued to use albinism stereotypes to limit interactions and engagement, which participants regarded as a reinforcement of their awareness of *being different*. By interrogating data through participants' experiences in the work environment, it became credible to surmise that just like the schooling environment, the working environment in Nigeria is intolerant and inconsiderate of persons with albinism and their associated visual disability.

For the participants, the working environment is a constituent of their social life. As already suggested by the findings, the working environment did not enable participants to form social relationships. Participants' attempts to turn outwards into the extended social environment were also met with unkindness and intolerance. It occurred to participants that just as it was difficult for them to join playgroups in childhood social experiences, attempting to develop an active social life in adulthood was also futile. In other words, the social stigma of albinism

became profoundly evident in participants' lives. Participants were to learn later on that albinism beliefs and stereotypes propagated by the Nigerian society will not only hinder their chances of fostering intimate and romantic relationships but also make women with albinism vulnerable to sexual exploitation.

Additionally, study data from participants' life stories demonstrated the extent to which social stigma and structural stigma connects childhood experiences with adulthood experiences in all areas of life for people with albinism in Nigeria. For participants, the realities of *being different* as PWA disable their health and wellbeing because their negative life experiences culminate in the development of various adverse psychosocial tendencies such as self-shame, low self-esteem, suicidal tendencies, loss of self-worth, depression, low social status, intentional withdrawal and disconnection from society, as well as poor health-seeking behaviour.

Following a careful exploration of participants' life stories, it emerged from the findings that the overall end product of *being different* is the various disadvantages and injustices that PWA continue to face in Nigeria as a result of societal inconsideration and poorly configured social institutions which in effect enable social injustices, discrimination and unequal access to social rights.

6.7 Summary

This chapter outlines raw data from participants' stories to demonstrate how they constitute the emerged theory of *being different*. The most apparent finding to emerge from this study is that persons with albinism (PWA) in Nigeria see themselves as *being different* because of how society treats them. The second major finding that emerged from participants' narratives is their belief that they are being treated differently primarily because of their physical appearance. It was also shown that while educated parents emerged as reliable predictors of

stable and supportive family structure, a child with albinism is not exempted from the disadvantages of stigma. One of the more significant findings that emerged from this study is that schooling and working experiences embody the initiation and manifestation of social and structural stigma for PWA. For the participants, the overall end-products of *being different* and its associated experiences of social injustices are stigma, discrimination, social inequalities, and adverse social wellbeing outcomes.

Chapter 7: Discussion of findings

7.1 Introduction

In this chapter, I position the constructed theory of *being different* with relatable elements of Goffman's (1963) theory of stigma, Rawls' (1971) theory of justice and Powers and Fadden's (2006) theory of social justice. These three theories shape and provide theoretical render to the constructed theory of *being different* in three different ways.

Goffman's contribution to the theory of *being different* is that it offers a theoretical perspective to explain how societal perception of albinism and participants' experiences constitute stigma. Rawls provides a useful framework to conceptualise the experiences of PWA within the broader context of an egalitarian society. Powers and Fadden provide a process and structure to examine the implications of injustices on participants' social wellbeing status.

In examining the emerged theory of *being different*, that is, being a PWA in Nigeria with the theory of social justice, I contend that the disadvantaging and unfair attitude and action by society and social institutions toward PWA, based on their differentness constitute a violation of social justices as defined by Mabhala (2014). Mabhala (2014) conceptualised social justice as the idea of creating a society or institution based on the principles of equality and solidarity, that understands and values human rights, and that recognizes the dignity of every human being. I argue that these injustices emanated from the Nigerian societal construction of PWA, which discredits them and reduces the whole person into a pigment-defined physical

appearance. These social injustices are derived from the actions of significant others¹⁴ and manifest as ongoing realities of stigma, managed by different mechanisms of resilience.

Goffman (1963) defines stigma as an “attribute that is deeply discrediting” which is used to reduce its bearer “from a whole and usual person to a tainted, discounted one” (p. 12 -13). This definition resonates the meanings that the participants in this study ascribed to their experiences. They believe that the attitudes of the Nigerian society discount and discredit PWA because of their albinism. Goffman’s (1963) three types of stigma were evident in the participants’ descriptions of the Nigerian society’s attitudes towards, and treatment of PWA. These include (i) abominations of the body; (ii) blemishes of individual character and (iii) tribal identities in terms of race, nationality and religion. These stigmatising characteristics emanated from the physical appearance of PWA which does not fit with societal norms in Nigeria.

The peculiarity of albinism in Nigeria has created a challenge not only to the society, but also to the Nigerian social systems that are not designed to accommodate the unique features of PWA. This resulted in the exclusion of PWA from fully participating in accessing social goods such as education, social welfare and employment opportunities.

Arguably, the theory of social identity proposed by Tajfel and Turner (1979) could be applied as a framework to explain *being different*. Social identity is attained by means of three mental processes that include social categorisation, social identification and social comparison (McLeod, 2008). Social categorisation is the classification of people based on the information

¹⁴ Significant others in the context of this study is an umbrella term which encompasses all members of the society whose actions directly or indirectly shape participants’ life experiences to include: family, school peers, teachers, employers and colleagues, romantic partners, and policymakers

that is held about them. Social identification is the process of associating with group(s) of individuals with similar attributes and thus, membership initiates the adoption of the behaviour and inclinations of the ascribed group. However, none of the elements of the theory of social identity adequately provide theoretical explanation to the data that was collected in this study. For example, the theory of social identity does not explain the essential feature of the emerging theory of *being different* that is, being socially disadvantaged on the basis of not fitting in with social norm.

Goffman's (1963) original theory of stigma offers a credible source of reference with which the manifestations of *being different* for PWA in Nigeria could be understood and explained. While Goffman's theory of stigma provides adequate explanatory power to the notion of *being different*, the analysis of data in this study revealed that the social disadvantages that PWA are subjected to lead to social inequalities and diminished social status. Thus, a different theory was required to provide theoretical render to the participants' experiences of diminished social status.

In the categories of 'being in a tug of war', 'disadvantaging schooling system' and 'suffering double tragedy', it emerged that participants experienced injustices of social inequalities and diminished social status within their homes and in formal social institutions. Rawls' (1971) theory of justice was used as a foundational framework to conceptualise these injustices within a wider context of egalitarian ideals. Powers and Fadden (2006) extend Rawls' theory of justice with respect to social equity and wellbeing. Approaching Rawls' position on equal distribution of rights and social goods from another perspective, Powers and Fadden recognise that because people have different starting points in life, thus, they will not have or require equal levels of health and wellbeing. In light of this, their contemporary theory of social justice is based on the ideals of providing levels of wellbeing that will be sufficient

according to individual needs. In resonance with the argument illustrated in Figure 2, Powers and Fadden appear to place priority on health equity over health equality. Drawing on this, Powers and Fadden's (2006) theory of social justice was adopted as an appropriate theoretical framework within which the theory of being different could be adequately contextualised. In alignment with the opinion of Imafidion (2017), the totality of the findings in this study calls for the appropriation of ethical, moral and social justice for PWA in Nigeria.

7.2 Being in a tug of war

Participants in this study characterised their childhood experiences as 'Being in a tug of war' to conceptualise the conflict between their parents who were struggled to come to terms with having a child with albinism (CWA). Previous comparable studies have explained the underlying cause of this conflict (Brocco, 2015; Ikuomola, 2015; Ross, 2017; Taniform, 2012). Ikuomola's (2015a; 2015b) investigation on the socio-cultural conception of albinism in Nigeria offers context-based insight into how the social construction of albinism in Nigeria could create conditions that cause a CWA to feel like being in a tug of war in the family. He suggested that in the Nigerian context, giving birth to a CWA causes social embarrassment for the parents as the society is likely to regard such parents judgementally for bringing forth a child who is perceived to be an anomaly (Ikuomola, 2015a; 2015b). Participants' explanations reflect resonance with Goffman's definition of stigma. Consistent with Goffman's idea of social stigma, they proposed that the fundamental reason lies within the social construction of albinism, which discredits the whole person based on their physical appearance. A recent ethnographic study in Tanzania by Brocco (2016) captures some of the social constructions of albinism that participants in this study have attributed to underlie the conflict their parents had regarding having a CWA. Collectively, these social constructions position a CWA as a weakling and this may compel parents to be distant from the CWA in order to avoid or reduce damages to the social reputation of the family. Goffman (1963)

would identify the risk of suffering social disrepute because of associating with an individual of a spoiled identity as social stigma.

Goffman (1963) provides some theoretical insight into the negative reaction to unexpected birth outcomes. Goffman (1963) would conceptualise this type of stigma as social disapproval due to associating with or being related to a stigmatised individual. Goffman would argue that the abductive reasoning behind negative paternal treatment emanated from the frustrations and fear of social disapproval and loss of social respect. These frustrations are expressed to manifest as various acts of injustices to the disadvantage of the CWA in the home.

Participants in this study reported that they felt that their parents treated them differently in a way that disadvantaged them from their siblings who do not have albinism. There are several family and parenting studies that have reported on causes and effects of disadvantageous offspring treatment. For example, Omoniyi (2014) demonstrated that parents' attitudes are likely to change for the worse when pregnancy outcomes are not consistent with expectations for an ideal child. This assertion suggests that a child with unexpected features [such as albinism] is most likely to be treated by parents in ways that resemble the experiences of *being in a tug of war*.

I argue that the idea that these participants in their childhood felt that they were not provided with adequate support to access equal opportunities by those who are in a position of responsibility contravenes the principles of justice as outlined by Rawls (1971). Rawls (1971, 1975) envisions justice not only as fairness but also as “the first virtue of society and social institutions” (Rawls, 1971 p.3) which is to be dispensed by allocating equitable benefits (and burdens) for the purpose of enabling equal access to social goods in any given social institution.

Some participants in this study revealed that their parents withheld some of their rights such as access to schooling. As presented in the findings, participants who shared this experience believe that they were denied access to schooling opportunities because their father considered them to lack capacity for being educated productively. I contend that this manner of parents' behaviour is in violation of two dimensions of social justice identified by Mabhala (2012) which are (i) ethical and moral dimension, and (ii) human rights dimension. I argue that parents have a moral and ethical responsibility to treat their children fairly and justly by providing them with the support that is required to enable them pursue life opportunities in equal capacity as with other children. I maintain that it is a fundamental human right for all children to access social goods such as education, health, and social security.

Participants' stories revealed that their experiences of being in a tug of war involved (i) unequal distribution of allowances; (ii) unequal distribution of domestic tasks and, (iii) being denied educational opportunities, which in itself as a social good is a basic right. Rawls (1971) would argue that these are inconsistent with a just and equal society. Rawl (1971) defines injustice as "inequalities that are not to the benefit of all" (p.62), which in simple terms means inequalities in the distribution of social goods and opportunities. According to Goffman's theory of stigma, these experiences of injustices triggered the awareness of being different and perpetuated their social disadvantage. Goffman (1963) described the processes of stigma awareness in that those with an inborn aberrant attribute become socialised into their disadvantageous situation through which they learn that they possess a particular stigma and the consequences of possessing it.

It emerged that unequal treatment and deprivation of schooling opportunities for some participants created a feeling of worthlessness. Rawl (1971) would argue that this is in violation of the elements of justice. He proposed that in a just society, all people should be

entitled to the following social goods: (i) fundamental rights and liberties; (ii) opportunities of freedom and choice; (iii) income and wealth; (iv) powers of civil responsibility in social institutions; and (v) bases of self-respect. According to Rawls, these social goods are essential elements of living that are desirable to every individual and considered crucial for self-worth. Therefore, it can be argued that deprivation of even one social good is to jeopardise the self-worth of any individual. It is immediately apparent that for participants to feel like ‘being in a tug of war’ at home, then it means that the distribution of social goods is inconsistent with Rawls’ vision.

It transpired in this study that some parents were less accepting of albinism than others. Similar observations were reported in previous studies. For example, Omoniyi (2014) attributed negative parental attitude to the lack of information on the full extent of a child’s disability and how to adequately manage it. This bears semblance with the findings of this study which are also similar to those of Kurian (2008) who explained that parents with low education are more likely to espouse negative attitudes towards a child’s disability due to their incapacity to acquire sufficient levels of educative information about disability management. Several studies found that the negative parental attitude towards a child’s disability, if not properly managed may evolve into shame and embarrassment; hostility, rejection, anger, and neglect towards the disabled child (Frude, 2002, Drew, 2008; Nbuzoka & Smith, 2003). However, there are limited studies that explicate the social consequences of having a CWA from parents’ points of view, which calls for a need for further investigation.

7.3 Disadvantaging schooling (and social) systems

The analysis of findings revealed two broad categories of experiences of being PWA which are: (i) those with negative home-life experiences who felt like being in a tug of war, and (ii) those with positive home-life experiences. For the participants in the first group, the process

of stigma awareness and learning the consequences of being different was initiated in the home. However, for participants in the second group, the process of learning the consequences of being different began within the schooling environment.

Stepping out of the family home environment into a formal social institution for instructive education brought all participants closer to the realities of what it means to be different as a CWA. Albinism, being a visible condition makes PWA immediately identifiable in any environment, by which reason they attract unwanted attention. For all participants, the first day at school marked the beginning of experiencing the effects of society's perception of albinism and PWA regardless of the experiences within the home environment. As presented in Section 6.3.3, participants' experiences of their first day in school are replete with recollections of being made an object of curiosity to the fascination of school peers. Even though some participants may have already begun to experience certain realities of unfair treatment in the home, Goffman identifies entry into the schooling environment as a major process of stigma awareness. According to Goffman (1963), "*school entrance is often reported as the occasion of stigma learning, the experience sometimes coming very precipitously on the first day of school*" (p.46).

Even in the classroom where the teacher is present, participants still found themselves in the centre of unwanted attention. Often, incidents of being made an object of curiosity quickly spiralled out of control into situations of name-calling, taunting, and even physical assault which resulted in distress for the CWA. In some cases, teachers were also complicit in the perpetration of these distressing bullying acts. The occurrences of teachers bullying students, even though under-researched have been reported to compromise the wellbeing of schoolchildren (Khoury-Kassabri, 2006; Pottinger & Stair, 2009). This thesis argues that if after completing required training and certification, a teacher who permits and participates in

the bullying of CWA or any pupil for that matter betrays the Socratic oath which mandates teachers to act with justice and fairness, as well as protect the physical and psychological inviolability of children (Hentig, 1993). According to Powers and Faden (2006), anything that compromises the wellbeing of a child contradicts the principles of social justice.

The effects of being picked-on and being made an object of curiosity by peers and teachers that participants have reported include low self-esteem and lack of self-confidence; loneliness and avoidance of contact in school; truancy, as well as loss of interest to continue schooling (Holt, Finkelhor & Kantor, 2007; Kaltiala-Heino, Rimpelä, Rantanen & Rimpelä, 2000; Kochenderfer & Ladd, 1996; Olweus, 1992). The life-long effects of these experiences that participants reported match those reported by Wolke and Lereya (2015), and the Education Policy Institute (2018) that these adverse psychosocial outcomes contribute significantly to widen the margin of inequalities in income and achievement for victims in adulthood. With these facts in mind, I wondered whether the functions and responsibilities of the schooling environment as expected of a just social institution are duly administered in Nigeria.

According to the English Department for Education [DfE] (2018), it is the responsibility of educators and school administrators to provide and maintain a safe environment of learning for pupils. Furthermore, school administrators are obligated to create a learning environment that fosters respect and cooperative relationships between all school members (Levine & Lezotte, 1990; Stockard & Mayberry, 1992). Several other government-led policies on education management in the United Kingdom in like manner with several other progressive countries stipulate that it is the duty of care for school administrators to identify any child who is most likely to suffer social or physical harm due to peculiar characteristics and take appropriate safeguarding action (Arboretum primary School, 2019; Learning Directorate of

the Scottish Government, 2017). This thesis argues that CWA fit into the category of children who are likely to suffer social or physical harm given their physical appearance.

Tarter and Hoy (2004) opined that an effective schooling system prides itself in a culture of trust by way of providing a learning environment that caters to the wellbeing and psychometric development of all pupils. Congruently, the vision statement in the National School Health Policy (Federal Ministry of Education in Nigeria [FMOE], 2006) mandates the responsibility of “Promoting Health of learners to achieve Education for All (EFA) and Health for All (HFA)” (p.4). The sum of this policy draws on the Dakar Framework for Action (United Nations Educational, Scientific and Cultural Organization [UNESCO], 2000) which advocates that basic education should be equitable so that all children are afforded equal opportunity of acceptable level of learning. However, evidence from this study suggested that the schooling system in Nigeria as reported by participants enables disadvantages for CWA and thus, falls short of the implementation of the National School Health Policy. These disadvantages in the school environment are inconsistent with the ideology of justice as propounded by Powers and Faden (2006) and Rawls (1971). If according to Rawls (1971) education as a fundamental right is a social good, then, CWA should be able to access that social good without fear for their personal security, bearing in mind that personal security as identified by Powers and Faden (2006) is an element of wellbeing.

In addition to the victimisation of CWA, the difficulty of the CWA in accessing sound education is exacerbated by the failure of the schooling system to provide disability support for visually impaired pupils. This fact suggests a lack of consideration for people with visual impairment who are enrolled in mainstream schools. The physiological implications of having albinism mean that PWA will have a lifetime struggle with vision and sight. In the

context of classroom learning, being visually impaired makes it difficult for them to see what the teacher writes regardless of proximity to the blackboard. Thus, without adequate learning support, PWA are naturally disadvantaged from fully participating in classroom learning.

According to the findings, these unfavourable learning conditions led to poor academic outcomes such as low grades and disinterest to pursue higher levels of education.

The simplest interpretation to explain participants' exclusion from full learning participation is that the participants found themselves in a schooling environment that was not designed to accommodate the needs of their visual disability, nor were the teachers equipped to recognise their needs for special support. This thesis argues that the inadequacy of the schooling environment to provide adequate human resources and equitable learning materials is suggestive of structural discrimination, which is a core element of institutional stigma (Corrigan, 2014; Corrigan, Markowitz & Watson, 2004). While Goffman (1963) did not directly approach the structural elements of stigma, his work alludes to institutional inconsideration and exclusion as contributors to stigma awareness when he stated that:

“There are civil places, where persons of the individual's kind are carefully and sometimes painfully treated as if they were not disqualified for routine acceptance, when in fact they somewhat are” (Goffman, 1963, p.102).

Drawing on Corrigan, Markowitz and Watson (2004), institutional stigma encompasses all intended and unintended policies that fail to take into due consideration the preferences of individuals with handicapped attributes who are equally entitled to access such institution. I contend that even though the Nigerian schooling environment may not have been structured to exclude PWA specifically, the absence of disability support suggests inconsideration for their visual impairment - this in itself is an injustice.

Viewing this category through the lens of Rawls (1971) and Powers and Faden (2006), then it is plausible to argue that the schooling system in Nigeria is unjust to CWA because the findings have demonstrated a breach of trust and the failure of the schooling system to fulfil its duty of care to the wellbeing of CWA.

7.4 Suffering double tragedy

Suffering double tragedy is a conceptual interpretation of what it means to be an adult PWA in Nigeria. As reported by participants, being a PWA is a primary tragedy because of the natural visual and dermal impairments that handicap the capacities of the eye and skin. Then, a PWA suffers double tragedy because of the unfair configuration of social institutions in Nigeria that causes additional disadvantages and enables the perpetuation of injustices. At the core of this reality is the social exclusion that PWA suffer in the Nigerian society.

The first conceptual description of '*suffering double tragedy*' is the exclusion of PWA from employment opportunities. As discussed earlier, the schooling system as a formal social institution enables the perpetration of injustices for PWA such that they are unable to participate fully in classroom learning during childhood. As a result, they are disadvantaged from either completing their education or acquiring good grades to progress to higher education. The ripple effect of this kind of injustice renders the majority of PWA unqualified for white collar jobs as adults. Thus, the majority of PWA are resigned to menial jobs that are not only lowly paid, but also lacking in security and respect. Fundamentally, disadvantageous schooling experiences already set conditions in motion to exclude PWA from employment opportunities that would have enabled them to acquire considerable social respect (Powers & Faden, 2006; Rawls, 1971) – this in itself is a tragedy.

The manner in which PWA suffer double tragedy becomes evident in how the working environment is unjustly structured. As noted in the findings, structural/institutional

stigmatisation in the working environment is evident in the attitude of administrators and gatekeepers of employment opportunities towards PWA. As emerged in this study, the exclusion of PWA from employment opportunities is more about the social construction of albinism, and the undesirability of their physical appearance than it is about their [in]capacity to perform.

The majority of participants keep experiencing rejection for potential jobs for which they are eligible because employers consider their physical appearance and visual impairment unattractive for business purposes. Based on the unjust configuration of the working environment and broader societal perception of albinism, nearly all the participants are unemployed. Moreover, to a reliable extent, this finding is relatable to the larger population of PWA in Nigeria (Etieyibo & Omeigbe, 2016; Olufowobi, 2018). Some PWA who are fortunate to gain employment suffer daily ridicule because of their low vision and consequential difficulties to perform as efficiently as other work colleagues. Rawls (1971) would argue that the underlying reason for this is that the employment institutions in Nigeria are inconsiderate to individuals with special needs, and therefore were not structured to accommodate PWA. In light of this, it becomes nearly impossible to reconfigure the working environment in Nigeria and make it adaptable for people with visual impairment. This is because a systemic restructuring will involve a policy change that would result in appropriating the built environment in terms of legible directional signs (Akhiero, 2011); enabling access to visual rehabilitation health services; as well specially adapted working materials in terms of font type and size to ease communication and administrative purposes (Haruna, 2017). For many employers, this type of restructuring is inconvenient due to its significant financial implications (Entekume et al. 2011; Wolffe, Ajuwon & Kelly, 2013).

Examining this categorical property through the lens of social justice, I contend that the social good of distributive liberties for employment opportunities (Rawls, 1971) enables the ability to lead self-determining lives (Powers and Faden, 2006). The ability to lead self-determining lives is derived from a societal system that allows its citizens to access the opportunities they require to shape their own lives according to individual values and preferences (Powers and Faden, 2006). This point of view re-echoes Mill's (1991) thoughts that "there is a greater fullness of life" in living a self-determined life (Mill, 1991, p.76). Thus, a society that is concerned about ensuring justice is expected to design its social institutions such that each individual will have access to the liberties that are instrumental for sufficient wellbeing. Unfortunately, PWA in Nigeria are denied sufficient wellbeing because of systemic injustices.

The experiences of suffering double tragedy permeate the formal working environment into the larger social environment where informal interactions occur. Given their experiences in childhood and the on-going realities of adult life as PWA, participants believe that the Nigerian society uses their physical appearance and visual disability to isolate them from social interactions and engagement. Participants contend that this was society's way of reminding them that they are different and unwelcomed in social circles, the effect of which inhibits their social wellbeing. Admittedly, participants recognise that they are different from the larger population because of albinism. However, it is the way the society uses their differentness as a tool for injustice that has implications for being different. Their point of view bears resonance with Goffman's opinion "that the special situation of the stigmatized is that society tells him he is a member of the wider group and that he is also different and it would be foolish to deny his difference" (Goffman, 1963, p. 149). Drawing from this standpoint, it becomes arguable that the Nigerian society is responsible for determining the realities of 'being different' for PWA. In agreement with the findings of Bradbury-Jones and

colleagues (2018), participants attest that the implications of socially isolating PWA make it difficult for them to form relationships and develop social ties, thus, compelling them to withdraw from social circles. This conflicts with Powers and Faden's (2006) concept of social justice that considers the ability to develop and sustain personal attachment as an element of wellbeing. Thus, the totality of 'being different' as a PWA in Nigeria constitutes multiple dimensions of injustices that continue to infringe on their social right to attain sufficient wellbeing.

The challenges of social relationships bear significant consequences for females with albinism (FWA). According to participants, being a woman in Nigeria is primarily a tragedy because of the principles of patriarchy that underpin unequal distribution of power and rights in a fundamentally trado-cultural society such as Nigeria (Makama, 2013). The practice of patriarchy is evident in all social institutions across Nigeria, much to the disadvantage of the female gender (Ademuson, 2016). On top of that, a FWA suffers double tragedy because of the social construction of PWA as possessing magical powers, which increases the vulnerability of FWA to being sexually exploited by men who are in quest of fortune, and healing (British Broadcasting Corporation, 2016; Kale, 2017). This social construction is a widely accepted superstitious belief across sub-Saharan African countries including Nigeria (Special Broadcasting Service Corporation, 2016; United Nations, 2013), although the extent of how it manifests differs across the continent.

A recent consolidated report on the endangered situation of PWA from several African countries including Benin Republic, Democratic Republic of Congo, Guinea, Kenya, Malawi, Mali, Mozambique, South Africa, Tanzania, and Zambia have shown the disadvantages of being a FWA (Under the Same Sun, 2019). Females with albinism are increasingly abducted, many of whom are later found dead without body parts of sexual importance such as the

breasts and vagina; it is believed that these body parts were harvested for ritual purposes (Under the Same Sun, 2019). It was observed in the report that the number of documented missing PWA in Nigeria does not tally with the number of discovered corpses. The statistics suggests that the bodies of missing PWA are either under-reported, unaccounted for or more specifically, that this manner of injustice manifests differently. Admittedly, the small sample size of this study does not allow a confident generalisation of the findings to corroborate the facts in the report. Nevertheless, considering the findings of this study, it appears that while men in Nigeria may not necessarily abduct and kill FWA for fortune and healing rituals, they resort to luring FWA into romantic relationships under false pretences in order to exploit them sexually.

All the female participants in this study testified to having been sexually exploited by men in Nigeria. For some participants, sexual exploitation manifested as rape while for several others, it was a case of men making deceitful promises of marriage only to discover later that these men are either married or about to marry someone else. In their opinion, participants believe that Nigerian men do not consider FWA as desirable but only see them as a means to satisfy sexual curiosity. In addition to the adverse psychological effects of bodily harm due to rape (Kilpatrick, Amstadter, Resnick & Ruggiero, 2007), this experience has left some participants with the economic burden of single parenthood. Responding to individual experiences, all female participants have resolved to avoid romantic relationships. This reality is arguably the reason none of the female participants are married even though they are all of marriageable age. Their response in the form of avoidance of romantic relationships appears to follow Goffman's (1963) proposal on how stigmatised individuals can reduce the risk of being vulnerable. Goffman noted that *"by declining or avoiding overtures of intimacy, the individual ensures that time will not be spent with the other, for as already stated, the*

more time is spent with another, the more chance of unanticipated events” (Goffman, 1963, p. 122).

In addition, the reality of what it means to be a FWA in Nigeria as evidenced in the findings resonates with similar studies from other African countries. For example, empirical studies conducted by Munsaka (2012) and Nzelwa (2016) in Zimbabwe and Tanzania respectively arrived at similar conclusions alluding to the social stigmatisation of FWA with respect to romantic relationship and marriage. These pieces of scholarly evidence validate the fact that being a FWA is indeed a double tragedy. These experiences continue to threaten the personal security of FWA; disable their social respect, discourage them from developing personal attachment and jeopardise chances to lead self-determining lives (Powers & Faden, 2006), especially if they may have to deal with the trauma of rape and associated financial burden of unplanned parenthood. Placing these realities in view, then it becomes reasonable to surmise that the wellbeing of FWA in Nigeria continues to suffer injustices.

7.5 Coping and Resilience

The several coping mechanisms the participants employ to get through life as PWA bear semblance with Goffman’s (1963) proposal for managing a spoiled identity. The most common mechanism for coping that participants adopt to build resilience against the realities of being different is by joining The Albino Foundation. Goffman mentions associating with “sympathetic others” (Goffman, 1963, p.31), that is, a relatable community of people with a commonality of experiences and shared stigma on whom the stigmatised individual can rely for moral support and instruction for coping.

In the same vein, the ways by which participants inure themselves and retaliate to name-calling is congruent with the concept of “breaking through” (Goffman, 1963, p.69). *Breaking through* as expounded by Davis (1961) is the peak of self-acceptance at which point a stigma

loses its importance to cause shame to the bearer, as a result of which a sense of normalisation is developed. Indeed, self-acceptance is Goffman's (1963) ultimate recommendation for stigma management. In his opinion [and as demonstrated in the findings], self-acceptance paves the way for self-preparedness and may potentially be the motivation needed to pursue self-development (p.140). Goffman's (1963) work offers different forms through which the reality of *breaking through* manifests. Inuring self and retaliating to name-calling as evident in the findings is a mechanism to cope and develop resilience to stigma which follows the concept of "hostile bravado" (Goffman, 1963, p.29) whereby the individual demonstrates either a reciprocal response of verbal discourtesy or extends a civil response to tactfully re-educate the bully and establish his/her right to be treated with respect.

Placing these coping mechanisms within the framework of the resilience theory offers deeper understanding on how participants have been managing the realities of being different. Conventionally, resilience can be conceptualised as the cumulative effort of an individual to reduce the effects of any form of personal vulnerability, and potentially overcome its limitations (Fergus & Zimmerman, 2005, Ledesma, 2014). Garmezy, Masten and Tellegen (1984) proposed three models of resilience to explicate the dimensions of coping strategies. These models are: (i) the compensatory model, (ii) the protective model, and (iii) the challenge model. In the compensatory model, the vulnerable individual utilises personal assets such as self-esteem, education, and competence skills to overcome the risk factors for adverse outcomes. In the context of this study, the compensatory model of resilience is demonstrated by the participants who inure themselves and retaliate name-calling. In the protective model, the individual draws resilience from external resources to buffer or alleviate the effects of adverse outcomes. These external resources include: parental support, mentoring and therapy, and support networks (Fergus & Zimmerman, 2005). In the context of

this study, the protective model of resilience is exemplified by all the participants given that they joined the Albino Foundation, and by those who rely on parental support and the practice of religious faith. The challenge model of resilience entails self-exposure to risk factors so as to learn the competence skills that may be useful in managing adverse outcomes. The challenge model is not applicable in this study's context because it would have necessitated the participants to actively expose themselves to risk factors of stigma and injustices.

Whilst it is possible for an individual to utilise a combination of the three models of resilience, Greene (2002) posits that resilience exists on a reversible continuum that ranges between survival, recovery, and thriving. According to Patterson and Kelleher (2005), each stage in the continuum represents a four-cycle phase which includes: (i) a deteriorating phase; (ii) an adapting phase; (iii) a recovery phase; and (iv) a growing phase. Within the theoretical construct of resilience, 'survival' means to suffer the adverse effects of risk factors and to function in an impaired state of wellbeing (Nishikawa, 2006). This stage leaves the individual susceptible to falling into the deteriorating phase. Indeed, given the findings as categorised under 'inhibiting social wellbeing outcomes' it is plausible to assume that the majority of participants are in the survival stage on the continuum of resilience. In addition, the multiplicity of social injustices that PWA suffer in the Nigerian society makes it impossible for them to recover and thrive. Thus, the inadequacy of the Nigerian society to enable and promote social security for people with disabilities continue to sabotage the attempts of PWA to build resilience.

7.6 Applying the Social Model of Disability to address 'Being different'

Albinism is not disease, but a genetic condition that manifests as a visual and dermatological impairment, both of which constitute a disability (Reimer-Kirkham, Astle, Ero, Panchuk, &

Dixon, 2019). In the introductory chapter of this thesis, Figure 1 was used to illustrate the inapplicability of the biomedical model of disability in addressing the challenges that accompany a condition such as albinism. In Section 5.4, Figure 7 presents a conceptual framework that identified society's perception of albinism as the factor that initiates, conditions, and sustains the realities of 'Being different' for PWA in Nigeria. Drawing on this inference, 'Being different' is a social problem and should be addressed with strategic interventions that target the root cause(s) of the disadvantages and injustices to which PWA are subjected in Nigeria. Attention must be turned to a model of disability that considers 'disability' as a social construction of how the society uses an individual's impairment to disrupt and disallow social engagement. As such, the tools that can potentially address the components of 'Being different' are embedded in the social model of disability.

As already introduced in Section 1.1, the social model of disability contends that whilst an individual may suffer an impairment resulting from loss or reduced functionality of a body part, it is the society that perpetuates the realities of disabilities (Oliver, 1984). Accordingly, a disability is activated and sustained because of socio-environmental barriers that limit the legitimacy of the individual as a citizen whose human rights and liberties for full societal inclusion and participation must remain inviolable (Union of the Physically Impaired Against Segregation [UPIAS], 1976). These socio-environmental barriers are illustrated in Figure 10 below

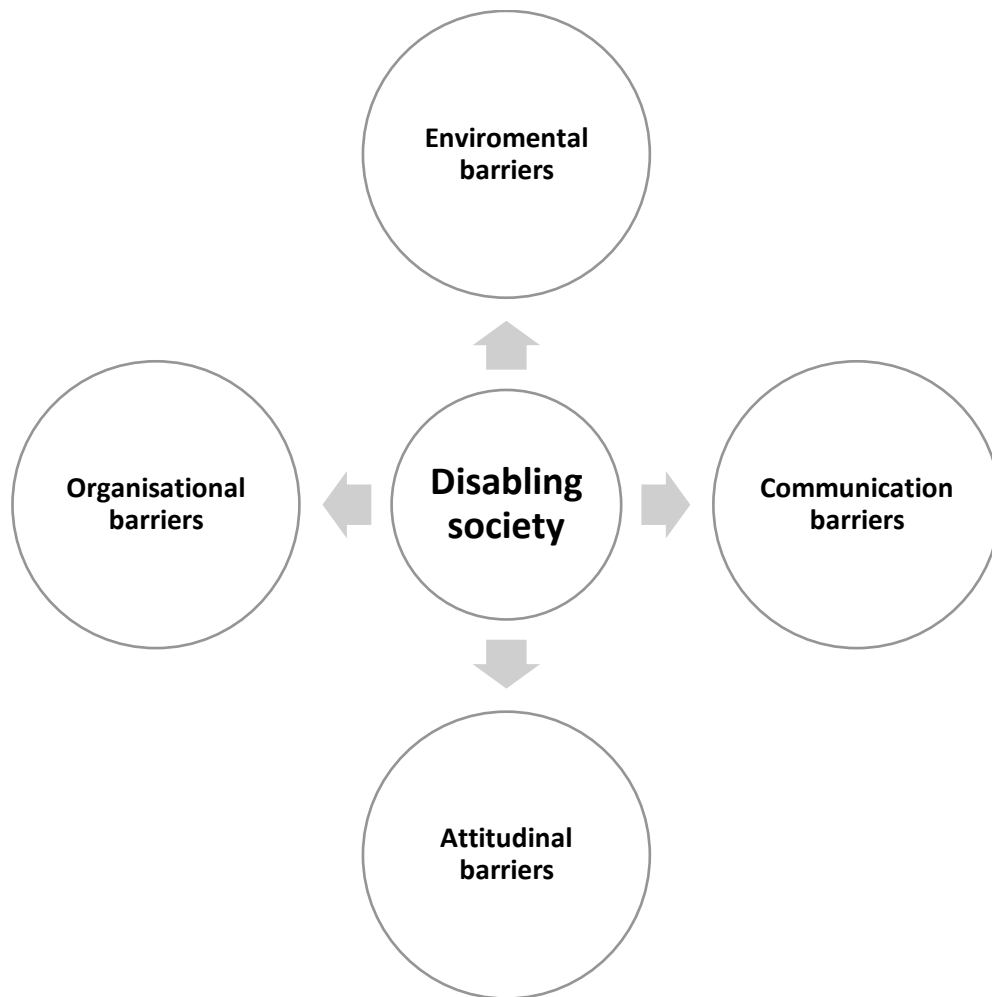


Figure 10: Components of a disabling society

The categories of '*Being different*' typify the components of a disabling society as conceptualised by the social model of disability. For example, 'being in a tug war', 'disadvantaging schooling (and social) system' and 'suffering double tragedy' epitomise the attitudinal barriers of stigma and name-calling that PWA experience in Nigeria. Similarly, these categories encapsulate organisational barriers of discrimination from employment, communication barriers of social exclusion and rejection, and the environmental barriers of socio-structural inconsideration that enable these barriers.

The United Nations Convention on the Rights of Persons with Disability [UNCRPD) (2006) recognises the social model of disability as a viable tool to improve the social wellbeing of

persons with disabilities (PWD). This is evidenced in paragraph (e) of the preamble in the UNCRPD (2006) protocol where it was stated that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others” (p.1). The protocol which has been signed by 172 countries including Nigeria, identifies with the social model of disability because of a shared ideology of justice that values the human rights of PWD and mandates the society to remove all types of barriers that threaten the full utilisation of those rights.

The social model of disability has been criticised for being narrow in its application on the basis that it models impairment as a unitary context of bio-functional incapacities and does not pay attention to other tools of socio-political oppression such as sexism, racism and homophobia (Fitzgerald, 2006; Flintoff, Fitzgerald & Scraton, 2008). However, its originator (Oliver, 2013) maintains that these other tools of oppression would not exist if society adopts that same principles of justice that the social model of disability advocates. Oliver (2013) contends that the modern application of the social model is one that harmonises the strengths of other models of disability to deliver an integrated social model that will improve the lives of PWD. For example, the rehabilitation services that the medical model of disability promotes (Bickenbach, Chatterji, Badley & Üstün, 1999) can be integrated to empower the abilities of PWD and not merely to stabilise their conditions. Relating this to PWA would mean assistive devices such as visual aids and prescription glasses to improve sight, and by extension, enable their physical abilities and competencies. The state-assisted benefits system that the welfare model of disability (Higgins, 1992) operates on could be utilised to provide skills acquisition and capacity building programmes for PWD so that they become active contributors to the society rather than dependent beneficiaries. A most recent ‘Active Model of Disability’ proposed by Levitt (2017) tasks the individual to engage in self-help and

support networks in order to reduce the limitations of disability. An observed oversight of this contemporary model is that an unjust society stifles self-help and renders any form of self-determination ineffective. It must also be noted that presently, the active model of disability is how PWA cope with 'being different' in Nigeria as evidenced in their membership of the Albino Foundation (TAF). While TAF continues to engage in disability activism, an integrated social model of disability remains the most applicable model with the greatest potential to achieve positive social enablement for a productive and progressive life for PWA in Nigeria.

7.7 Original contribution to knowledge

To start with, the entirety of this thesis has been written in simple language so that its content can be comprehensibly accessible to people in and out of academia. This is because at the core of this project lies a necessity for the society to address issues of social inequities and the consequent injustices and inequalities for PWA who happen to be disempowered by the unfair configuration of the Nigerian society. Seemingly, the necessary interventions if they are to be effective and efficient in their delivery and sustenance would require an interdisciplinary and multi-sector collaboration between the learned society, socio-political lawmakers and policy drivers as well as custodians of sociocultural values and practices. It is envisaged that the findings and recommendations drawn from this study would inspire a culture of reciprocal duty of kindness and equitable care in line with the Ubuntu African philosophy of humanity that entreats everyone to be kind, respectful and considerate of one another (Mugumbate & Nyanguru, 2013; Nussbaum, 2003). Having stated this, then it becomes imperative to highlight the value that this study adds to scholarly knowledge.

Charmaz (2006, 2014) outlines four criteria with which a ground theory study could be evaluated to include: (i) Credibility; (ii) Originality; (iii) Resonance; and (iv) Usefulness. Her

opinion on assessing originality scrutinises a study on the basis of its social and theoretical significance and the potential to offer new insights as an extension or refinement of established knowledge.

According to Charmaz (2006, p.182), a grounded theory study should be evaluated, firstly, for its credibility which refers to the rigour with which the concepts, categories, arguments and analyses are supported by empirical data collected by the researcher. In connection with this, Charmaz (2006, p.182) asks whether “the data is sufficient to merit your claims?” As far as this study is concerned, all assertions and inferences are based on participants’ construction of their life experiences and my subjectively constructed interpretations of these experiences. The point being made here is that the interpretations and meanings I have made of participants’ life experiences are subjective to their constructions and where necessary, literature was used to validate these interpretations. Care has been taken to ensure that no claims have been made objectively.

The second criterion of originality borders on the extent to which the emerged concepts, categories and arguments extend or challenge existing practices. Originality examines the novelty of the study or if it is a repeated version of another. In an attempt to satisfy Charmaz’s evaluation criterion for originality, this study draws on a recently published bibliography of one hundred and sixty-eight studies relating to albinism from all over the world (Hohl, 2018). A quick cross-reference search of research titles through the bibliography revealed that only three studies relating to albinism were conducted in Nigeria. These studies were conducted by Ezeilo (1989), Fayoyin and Iheabuzor (2014), and Ikuomola (2015).

Ezeilo (1989) adopted a desk research methodology on psychological trait to determine the intellectual ability of PWA. The study concluded that PWA have similar intelligence quotient

consistent with the rest of the general population; however, they were found to be less emotionally resilient. Fayoyin and Ihebuzor (2014) adopted a case study methodology to investigate the effectiveness of advocacy interventions aimed at changing the social discourse surrounding albinism; their study concluded that advocacy interventions are rendered ineffective because of conflicting sociocultural beliefs. Lastly, Ikuomola (2015) conducted an ethnographic study on sexuality experiences of PWA from the south-west region of Nigeria. His findings highlighted sociocultural beliefs of albinism as barriers to fostering mutually beneficial romantic relationships. I acknowledge that these studies have significantly contributed to the teeming body of evidence in the collective effort to address experiences of social challenges for PWA.

Having acknowledged these previous studies, this current research study claims originality in terms of context, methodology and findings. While previous studies have identified social beliefs as problematic for PWA, this study provides contextualised insight into the processes that constitute the manifestations of those social beliefs across the life course of PWA. In addition, this study is the first of its kind to adopt constructivist grounded theory methodology to theoretically contextualise and conceptualise the multiplicity of life experiences and what it means to be a PWA in Nigeria.

Resonance seeks to ascertain if the categories portray the fullness of the studied experience (Charmaz, 2014, p. 337), and if the findings would make sense to the participants who have shared their stories with me. The categories that have emerged in this study were constructed from *in vivo* codes. Thus, it is plausible to state that the generated theory of being different represents participants' realities in light of the contexts and conditions that underlie their life experiences.

The fourth and final criterion of evaluation is usefulness. Usefulness assesses the applicability of the grounded theory to the real world. This in plain terms examines if the categories and emerged theory contribute to existing knowledge and thus, able to inform practice. Arguably, the overall usefulness of this study is embedded in the constructed central category of 'Being different' which embodies a theoretical concept to qualify PWA. The central category of "Being different" and its derived emerged theory meet the requirements of the three dimensions of social justice as proposed by Mabhala (2012). Firstly, this study stands to satisfy the science dimension of social justice, that is, using scientific means to identify and qualify social injustices, thus, grounding claims in empirical evidence. Secondly, the subcategories of *being different* highlight the injustices and disadvantages that PWA experience in Nigeria, thereby, necessitating the collective need for the society to ensure that the integrity of social rights for PWA are enabled, upheld and maintained. Thirdly, the findings of the study have the potential to appeal to the ethical and moral conscience of policy makers so as to ensure that concerns of injustices, inequities and inequalities for PWA are systemically and holistically addressed. Thus, the emerged constructed theory of *being different* is useful to inform the appropriateness of interventions and policy realignment that will promote, ensure and sustain inclusiveness and social equity for PWA in Nigeria.

7.8 Trustworthiness of the study

Given that this study highlights the realities of social injustices that PWA experience [and are likely to continue to experience] in Nigeria, it becomes an obligation to delineate the trustworthiness of how this study was conducted so as to increase public confidence in the findings and recommendations that have emerged from this study. In light of this, Guba and Lincoln's (1985) four criteria for evaluating trustworthiness will be used to demonstrate that this study is worthy of scholarly attention and recognition.

Credibility scrutinises a study on the basis of ascertaining if the interpretation that were rendered to the finding are consistent with the data that were obtained from participants. According to Guba and Lincoln (1985), prolonged engagement with participants, data sources and the data is one way to achieve credibility. The credibility of this study can be attributed to its methodological design of constructivist grounded theory which necessitated gaining insider access to participants' experiences and the resultant mutual construction of knowledge and meaning between the researcher and the participants. In this study, Chapters 4, 5 and 6 have been used to demonstrate that how my relationship with participants was established and sustained throughout the stages of data collection and analysis. Particularly, Chapters 5 and 6 exemplify how the analytical categories were constructed with participants' verbatim narratives. Thus, the findings are true representation of participants experiences.

Dependability examines the philosophical and methodical decisions that were made while the study was conducted. Chapters 1, 3, 4 and 5 present an audit trail to detail, clarify and justify the decisions and methods that have been adopted to direct the course of this study. These chapters epitomise a purist methodical adherence of this study to the methodological principles of constructivist grounded theory.

Transferability is concerned with the extent to which this study can be replicated in other settings. It must be noted that this study is context-based. The robust narrative descriptions that have been presented in this study provide clarity on the characteristics of participants as PWA and the social environment of the Nigerian society that determined their experiences. Thus, the transferability of this study could only be made possible within a similar demography and socio-environmental context.

Confirmability judges whether the research could be ratified by other researchers, and endorsed as a valid scholarly piece of work that contributes to knowledge (Lincoln & Guba,

1986). Confirmability rests on the extent to which the credibility, dependability, and transferability of a study have been proven (Tobin & Begley, 2004); each of these have already been detailed. Koch (2006) opined that reflexivity increases the confirmability of a study. Give these points of view, a reflexive account of my relationship with this study as presented in the succeeding Chapter 8 further strengthens the confirmability of this study.

7.9 Summary

This chapter has attempted to validate the constructed theory of *being different* with extant theories of stigma, social justice and resilience. Similarly, the findings were positioned with other scholarly evidence that have come to similar conclusions. The totality of this chapter positioned the emerged theory of '*Being different*' to exemplify the multiplicity of the realities of stigma and social injustices that PWA experience in Nigeria. The chapter concluded by highlighting the applicability of an integrated social model of disability as a plausible strategy to address the realities of '*Being different*'.

Chapter 8: Reflexive account

8.1 Introduction

This chapter is a critical reflexive account of my reflections and the interchange of influence between me and the research journey. Herein, I acknowledge the subjectivities and expectations with which I began this research journey, and how both elements have evolved as I interacted with participants and data (Sartre, 1969). I hope the reader will consider this chapter a credible attempt to improve the merit and trustworthiness of this study as recommended by Hall and Callery (2001) for grounded theory inquiries. The totality of this chapter rests on the words of Mauthner and Doucet (1998):

“...reflecting upon and understanding our own personal, political and intellectual autobiographies as researchers and making explicit where we are located in relation to our research respondents. Reflexivity also means acknowledging the critical role we play in creating, interpreting and theorizing data” (Mauthner & Doucet, 1998, p.121)

8.2 Reflexivity

Finlay and Gough (2003) conceptualise reflexivity as a critical self-reflective analysis of the intersubjective dynamics between the researcher and the researched phenomenon. The notion of ‘intersubjective dynamics’ is particularly crucial to my reflexive account given the importance of the relationship I had formed with participants. Admittedly, forming a relationship of trust with participants involved continuous negotiations of adoption as if to convince them that I was consistently worthy of their audience and attention. Indeed, I brought with me certain expectations mixed with apprehension of not knowing if I would be welcomed. Similarly, I also bore in my mind that participants would have their own expectations as well. My apprehension stemmed from not knowing if our expectations would

be in conflict, and even if in congruence, whether I would be able to satisfy their expectations.

As argued by several proponents of grounded theory, qualitative research of the constructivist paradigm is not removed from the sociocultural influences that constitute the moral philosophy of a researcher (Bryant, 2002; Charmaz, 2006; Mills, Bonner & Francis, 2006). Expectedly, there is transference of self, if not an identifiable reflection of the researcher, into the area of inquiry. Thus, a researcher is subjective to these influences. Similarly, the researched group is not without its socio-cultural inclinations; and while the researcher and the researched may share certain similarities in philosophy and experiences, there is a fair chance of dissimilarities. If these similarities and dissimilarities are not acknowledged and duly managed, a researcher may end up pushing for a personal agenda based on preconceptions and thereby miss being led by data. As conventionally established, constructivist grounded theory prides itself in the cooperative construction of data and meaning between researcher and participant(s), but not without admitting the subjectivities that may have impacted this mutual venture.

Finlay and Gough (2003, p.6) identified five types of reflexivity as follows (i) introspection (ii) intersubjective reflection (iii) mutual collaboration (iv) social critique and (v) ironic deconstruction. Out of these five typologies, reflexivity as a social critique offers the most applicable relatedness to this study. Reflexivity as a social critique relates to research inquiries that touch on the dynamics of power in any given social context. Given the lens of social justice through which this study was conceived, power may be viewed in terms of societal and institutional dynamics, and how these determine the realities of disadvantages for the less powerful. In addition, it extends to being aware of and managing the power dynamics that were observed between me and the participants who happen to belong to a vulnerable

group. In light of this, it happened that the allocation of authority was continuously negotiated between the research participants and me all through the research journey.

My reflexive account draws on three levels of reflexivity as proposed by Wilkinson (1988) which are: personal, functional and disciplinary. The personal level of reflexivity considers the researcher's individuality and the aspects of it that have permeated the research. During the journey, musings on emerging questions and decisions should be documented. Functional reflexivity chronicles the researcher's role and ensuing effects on the research process, more especially on power dynamics in researcher-participant interactions and relationship.

Disciplinary reflexivity highlights the methodological decisions of epistemological and ontological bearings and brings to fore the suitability of the present research with extant theories and methods of similar inclinations. That is the contribution of the current study to existing literature on the topic area.

Personal reflexivity encompasses critical scrutiny of one's presuppositions and inspirations that initiated the research questions. Usually, this involves considering one's subjectivities as contextualised in interpersonal and sociocultural exposures. Throughout the research journey, I kept a research diary (Mason, 1996) into which I documented chronological accounts of ideas, and questions during moments of reflections and supervision meetings, as well as, excerpts from the books and articles I consulted for guidance and clarity.

My journey started with being dissatisfied with the manifestations of oppression and injustices in my social environment. The religio-cultural influences that underpin my moral philosophy are as stated in Chapter One. Principally, I realised that if my aspiration to become a social justice advocate is to be devoid of hypocrisy, then I have to expiate for how my internalised social construction of albinism as a child had influenced my perception of people with albinism (PWA). This research endeavour was my journey to perceptual rebirth.

Even though I had been living in England, which is a progressive society where injustices and oppression are not as visible as in my home country Nigeria, I was not oblivious of the reality that I would have to return home at some point. Thus, I could not deny my proximity to the ongoing realities of social injustices. Of all the vulnerable groups in Nigeria that are treated with stigma, PWA occupy a relatable position in my heart. This is because I share in the social construction of albinism and PWA. My parents never discussed albinism and PWA with me; however, I realised that I subconsciously formed my perceptions of PWA. I draw on a childhood experience to illustrate this.

While on a domestic errand for my mother, innocent curiosity caused me to stop on the way and harvest cashew fruits in an unfenced orchard. As I returned home with my loot, I passed by a row of shops from where a man beckoned to me. Even though I could not make out the man's face as it was hidden in the shade of the extending roofing sheets, I moved closer to the sound of the voice (it is an expected sign of cultural respect in the Yoruba tribe to respond when an older person beckons). The moment I was within his reach, he grabbed my hand and began to query me for the cashew fruits. I was overcome with an immeasurable depth of fear because (i) the closeness of his face to mine revealed a skin, hair and eye colour that I had never seen before and, (ii) the tightness of his grip on my wrist was overpowering. Amidst my tears and fear, I hardly heard his questions before I let go of my loot, wriggled my wrist free of his grip and ran as fast as my legs could carry me. Unbeknown to me, the man owned the orchard from where I had harvested cashew nuts without permission, and he only wanted to reprimand me for trespassing. Thus, my first experience with a PWA was laced with recollections of fear and distress. In retrospect, I realised that I would have been more at ease if the experience was with a typical dark-skinned senior citizen considering that it is an acceptable Yoruba cultural norm for the elderly to correct an errant child. In essence, the fear I felt could be attributed to the strangeness of the man's physical appearance. It was with this

perception of fear that I regarded a classmate of mine who has albinism in secondary school several years later. If I am being honest, I must have at one point or another spread the news of fear for PWA because of that singular experience. Indeed, I am also responsible for the social construction of albinism and PWA. Perhaps, the research interest in PWA is an attempt to rectify their spoiled identity.

Having identified a target group for the study, the next step in the journey was to formulate appropriate research questions. In order to achieve this, I drew on Maslow's (1969) suggestion that implored researchers to ask a true question. Firstly, according to Maslow (1969), a question is true when it constitutes a "real and living doubt" (p.134), and secondly, when it has not been answered by scientific literature (Gadamer, 1988). Some of the questions I asked myself as I struggled to formulate the research questions were:

"Of what interest are PWA to me? Amidst heart-wrenching news on reported experiences of brutality and violence of PWA in eastern and southern Africa, what is true of PWA in Nigeria? Do they have similar experiences? If yes, what do these experiences mean for them? Is there any scholarly literature that has conceptualised and contextualised what it means to be a PWA in Nigeria? If yes, then to what extent and depth and with what methodology? If not, could this then be an original research?" - [October 19th, 2015 - personal memo after discussing the research topic with my Principal Supervisor who asked me to go have a rethink and return to convince him in a month]

Studying in the UK for a master's degree in Public Health afforded me the social exposure of experiencing a new way of life that recognises and respects human dignity and fairness. The modules of the postgraduate course sensitised my awareness of the social influences that determine population health and how one may attempt to tackle the elements of inequalities

that threaten wellbeing. It was with this newly acquired worldview and social status that I presented myself to the community of PWA I hoped to recruit for this study.

At the beginning of the data collection stage, I was anxious about the reception that awaited me as I attempted to advertise the study to members of The Albino Foundation (TAF) and engender their interest to participate. Obviously, I was an outsider as I neither have albinism nor will ever know how it feels to be a PWA. I was aware that this community of people has lost faith in the system because they have been interviewed severally by media houses and political advocacy groups, and it did not seem like sharing their plight yielded any results. Many of them chose to keep attending monthly meetings because of emotional and moral support and perhaps, a chance to get free sunscreen for their skin. Building trust was essential for acceptance and adoption as a genuine sympathiser. Following the advice of the Programme Assistant of TAF who is also a PWA, I began to attend monthly meetings to establish familiarity and build rapport. At the end of the meetings, I would offer free seats in my car to people going in my direction and on the journey, they would spark up a conversation. Even at that point in time, data was being presented to me before any interview was formally scheduled. The process of adoption had started, and my outsider status was gradually taking a different form of an insider.

After attending two monthly meetings with members of TAF, I realised that women were more interested and inclined than men to participate in the study. It dawned on me that my social status as a young dark-skinned man with western affiliations might have been both a disadvantage and advantage for the recruitment of participants and consequently, be the reason for the gender imbalance in the number of participants. I was able to see how the patriarchal sociocultural configuration of the Nigerian society does not encourage men to share their vulnerabilities and life struggles with other men, less so with a younger man in a

society that accords interactional respect based on age difference. In contrast, it appears that the women seized the opportunity to share their life struggles. The prospects of sharing their stories offered them a cathartic respite from the oppression of silence and disregard they endure in a societal system they believed has failed them. Reflecting on the meetings preceding the interviews, it became apparent that these women's hope of getting some justice was hung on having faith in a young man [me] who had come from a globally-respected and functional [western] system. The interviews seemed to have presented them a platform for their voices to be heard and shared - as a way to make their struggles visible to the world.

During one of the interviews, a participant expressed her scepticism about the outcome of the study. She said in pidgin English: "*No be the first time wey dem go interview us, nothing dey happen* [It's not the first time we've been interviewed, and nothing comes out of it]". I realised that my answer would determine her active participation and richness of contribution. At that moment, my status as an outsider was being tested. I was able to manage this by firstly, being honest about the potential of the study. I reiterated that this study does not promise an immediate implementation of interventions but the potential findings could be used to authenticate and disseminate credible information for the much-needed interventions that are required by PWA. Secondly, I reassured her that this study is an attempt to join the struggle for justice: an indication of solidarity with PWA. I was not sure what effect these answers had on her. However, her face lit up when I told her she would be the one to drive the conversation because all I needed to start with was listen to the story of her life from childhood until the present day. I believe this gave her a sense of power and perhaps, it was the first time in a long time she felt in control and free to share her personal information in privacy devoid of the possibility of other people's stories overshadowing hers. It occurred to me that her experiences of being previously interviewed were of a formal, structured and controlled manner much to the agenda of the interviewer and in the presence of other PWA.

The privacy to share their experiences individually was something each participant relished and appreciated. One of the female members of TAF, although dark-skinned but whose children have albinism was so positively interested in the study. She asked if I could interview her teenage daughter who is in a boarding school on the outskirts of the city. She was disappointed to hear that only adults are eligible to participate because of the potential emotional implications of recollecting unhappy memories. Even now, I see that the inclusion criteria for sampling were a limitation to the scope of this study.

Some of the literature I consulted on interviewing techniques recommended active listening but not so much emphasis on how to manage emotional responses from the interviewee (DeMarrais & Tisdale, 2002; Oakley, 1981). However, during the face-to-face interviews, the majority of participants cried as they recollected and narrated their life experiences. Given that the majority of participants were women, it posed a challenge of professional boundaries for me to acknowledge the depth of their emotional responses without offering physical comfort. Usually, I would lower my gaze and mutter: *"I am sorry you went through this"*. Lowering my gaze seemed to offer them the liberty to let out their emotions without concerns of a judgemental or patronising look. Since the majority of participants are women, some of them brought their children to the interview. In my functional responsibility to the participants who have children, I usually took with me snacks, little toys, drawing books and crayons. With these, participants were always at ease to share their stories without being distracted no matter how long the interview took because their children were creatively engaged with playthings. Also, driving them to the bus stop closest to their houses gave them comfort and relief from the difficulties of queuing for a commercial bus under the scorching sun. This manner of duty of care engendered their trust and motivated them to encourage others to participate. In this manner, I was an outsider who had been given the privileges of an insider.

Even though scholarly and journalistic literature have provided a plethora of awareness on the social construction of albinism and PWA within an African context, I realised that participants did not acknowledge any of such social construction for their condition. This limited the extent to which I could probe during the interviews. Otherwise, I might have ended up forcing the data to fit into popular culture. It appears that through the counselling and enlightenment provided by TAF, participants have been able to gain knowledge on the biological causes and management of albinism; and as such, have rid themselves of the unfairly constructed social superstitions of albinism.

Bonner (2001) notes that a research inquiry “would be fundamentally incomplete” (p.273) if one is to avoid a reflexive analysis of the methodological account of one’s decisions. Being a novice researcher and without professional practice in academia, I struggled to intellectually figure out my ontological and epistemological stance, as well as what methodology is most applicable and how best to apply its methods. Firstly, I relied on my faith-driven moral philosophy of love and fair consideration for the oppressed as propagated through the Holy Bible. With this, it became easy to see how my moral philosophy is reflected in the principles of public health and wellbeing as it relates to equity, equality and social justice. This knowledge formed the backbone of my ontology. Since this study rests significantly on life stories and experiences, then it made sense that my epistemology will be situated in defining meaning with participants in the context of their social environment. Given that I am not familiar with the condition [albinism] under investigation or what it means to have it, constructivist grounded theory (CGT) provided the methodological tools that I required to construct and interpret meaning with the people who are directly affected by the condition. Having stated this, it is not to say I did not contend with difficulties as I struggled to tease apart the overlapping philosophical underpinnings of various qualitative research

methodologies. Moreover, I had to convince the Faculty of Health and Social Care Research Ethics Sub-Committee (FRESC) why CGT is best suited for this study. The first application to the FRESC came back with the following comment on the choice of methodology:

“This is just an observation, but you may wish to further discuss your choice of grounded theory with your supervisors. You are exploring life experience using biographic interviews; would phenomenology or life biography be more appropriate? We recognise that you state that one of your aims is to produce a theory; this is not exclusive to grounded theory and other approaches do facilitate this. Indeed, constructivist grounded theory has been criticised for not resulting in an abstract theory that can be further tested to enable its wide application” [FRESC comments on application RESC0116-671. Received on 02/02/2016]

Thankfully, with the support of my supervisors, the justification I gave for choosing CGT appeared to have satisfied the FRESC to grant approval to commence the study. Simply put, my response on the 1st of April 2016 stated that I favoured CGT because of its potential to enable me to offer a theoretical explanation of what it means to be a PWA in Nigeria.

Another way I employed reflexivity was by engaging with the University research culture at different fora, which presented me the opportunity to share the developmental stages of my work with Faculty staff and fellow researchers. While the complexities of albinism and being a PWA within an African context always provided a stimulating and at many times, eye-opening discussion, I was always looking out for questions, suggestions, and comments that could offer me a different angle of insight. One of those questions was:

“Are there any positive cases from within your participant group? What has changed in their lives since the last time you met them?” [Asked by a member of the audience after my presentation at the Postgraduate Research Symposium, 9th February 2018]

This question was the impetus I needed to telephone each of my participants, to say a friendly ‘Hello’ in a way that would not be misunderstood as accentuating their neediness to be ‘checked up on.’ It occurred that a simple “how are things with you?” was all they needed to catch me up to speed about their present situation. It was disappointing to find out that their situations had not improved since the last time we met. Usually, our conversations ended with phrases such as “*Dis country don taya me my brother* [I am tired of this country my brother]” and “*It is well* [a common statement of Christian faith in God that things will get better]”. If nothing, these fact-finding missions always left me with a sense of adoption that they see me as their brother. Thankfully, the threat of power imbalance was broken.

The writing stages of this thesis, although eventually rewarding was characterised with feelings of despondency and loss of confidence. After months of writing a chapter, the feedback from my supervisors always seemed like a reminder of how incapable I was at expressing myself articulately.

At one of the Faculty PGR conferences, I consulted a faculty staff who had used constructivist grounded theory to discuss some of the methodological challenges I was experiencing during the analysis of data. Many of the questions I asked were unanswered but not without honestly admitting that the methodology would have been better applied in light of present knowledge. This was three years after completing the doctorate. It seemed unfair that I was held to such high standards of writing and analytical skills when it appeared that several faculty members had only just attained such expected level of analytical proficiency

years after completing their doctorates on top of extensive professional practice. Unarguably, my understanding of research could not compare with theirs, yet, it seemed they expected me to write just as skilfully as they would. Riddled with feelings of incompetence, I would ask myself “How do I stay true to my African voice and still make sense to my supervisors?” I obtained copies of their Ph.D. theses and combed through them tirelessly, hoping to find a reflection of myself. Torn apart and at my wit’s end, I walked into my Principal Supervisor’s office one evening and shared my frustration. He said to me “Anthony, speak your truth and don’t let anything else push you around. Nobody can contest your truth and your voice”. This statement gave me the strength to muster confidence and forge ahead with my writing. The freedom to speak my truth with my own voice was my liberation.

The search for a theoretical framework informed the themes of the literature review chapter. The expanse of literature that was used to conceptualise social evidence on albinism in Africa was obtained from nontechnical sources such as media news more than scholarly articles. I find that this is because journalists and social advocates more instinctively cover the social construction of albinism, stories of brutality, violence and other social injustices that PWA experience than the academia. I became aware that drawing from nontechnical literature affected my style of writing such that some parts of this thesis read more journalistic and descriptive than academic and critical.

I started the research journey as an attempt to lay the foundation for my passion and career as a public health advocate of social justice. The effect of this study on me continues to influence me to widen the scope of advocacy for social justice for PWA in Nigeria. I feel that this study is only one side of the coin, that is, seeing the story through the eyes of PWA. As I progress in my career, I believe that as a matter of duty I must complement this study with the other side, which is, seeing the story through the eyes of the society. For indeed, I believe

that if social justice is to be secured and sustained for PWA, then the Nigerian society must be brought to the consciousness of its shortcomings, and possibly open the pathway to progressive societal change. Moreover, societal change becomes easier when society is aware of its failures and inadequacies through the evidential actions of its members.

8.3 Summary

In this chapter, I have demonstrated the ways through which I have employed reflexivity throughout the research journey. I have used Wilkinson's (1998) three levels of reflexivity to demonstrate the transference of influence between me, research participants and the research study itself. I admitted my struggles with convincingly applying the methodology to data. While I hope that this study is considered a credible doctoral attempt, I remain aware that the coming years will present me with fuller understanding and opportunities to apply the methodology more accurately as I progress with my aspirations.

Chapter 9: Conclusion

9.1 Introduction

This chapter aims to conclude this thesis. I will start by demonstrating that the findings of this study have addressed the research questions by positioning the aim of this study alongside the emerged theoretical arguments detailed in Chapters 5 to 7. Also, I will highlight the significant contributions that this study adds to the body of knowledge. These will underscore the implications of this study in relation to the context of the Nigerian society. This chapter will identify the limitations of the study, and ends with a presentation of recommendations.

9.2 Significant contributions to new knowledge

The purpose of this study was to use the life stories of persons with albinism (PWA) in Nigeria to construct a theory about their social wellbeing status. In this respect, the constructed theory is expected to explain the meaning of being a PWA in Nigeria and identify its consequential effects on social wellbeing. To this end, '*Being different*' emerged as a theoretical concept that personifies what it means to be a PWA in Nigeria given the various conditions under which they are being regarded and treated by the society. This concept of self was constructed by participants themselves and it was used to generate a theory that highlights the realities of injustices that PWA experience at different stages of life.

By engaging the methods of constructivist grounded theory, this study has attempted to delineate the processes [how] and situational conditions [why] with which PWA in Nigeria have conceptualised their life experiences. The theoretical explanations that emanated from the concept of '*Being different*' underscore institutional disregard for the social security and wellbeing of PWA right from childhood into adulthood. As represented with the constructed analytical categories, it becomes apparent that the realities of experiencing *being different* can be initiated within the family, being the foremost social institution in any society. These

realities are further amplified within the schooling and employment social institutions. The significant contributions of this study to new knowledge are articulated as follows:

- i. The substantive theory of 'Being different' offers a conceptual framework with which the manifestations of social injustices to PWA could be situated and investigated
- ii. The conceptual categories of 'Being different' provide points of reference with which social policy and interventions could be implemented for the betterment of PWA at different life stages
- iii. The coping mechanisms for 'Being different' provides a strategic model that could be harnessed and integrated with existing interventions for disability care in Nigeria. This echoes the words of Fraser and colleagues (1999) that "If we can understand what helps some people to function well in the context of high adversity, we may be able to incorporate this knowledge into new practice strategies" (p. 136). For example, the findings revealed that the practice of religious faith and activities have the potential to effectively assuage the realities of *being different*. Thus, this offers a reliable point of reference to ground actionable interventions.

9.3 Implications for governance and social care policy on albinism and PWA in Nigeria

PWA have always been a part of the Nigerian society even though the transactional configurations of the society continue to pose limitations to their social mobility and by extension, their social wellbeing. In its literal sense, *being different* connotes a sense of distinction but in a way that segregates, marginalises and disadvantages PWA as is the case in this study. This constitutes moral and ethical implications for the Nigerian society as a whole. The responsibility of culpability has to be shared by everyday members of the society and those at the helm of power across all social institutions. Fundamentally, the wilful (or unintended) injustices that PWA experience in formal social institutions such as in school and

in the working environment is suggestive of the lack of compliance to the Commonwealth's core values of human rights; concern for the vulnerable; and inclusiveness that a member-nation such as Nigeria is expected to embrace (Foreign and Commonwealth Office, 2013). Consequently, this can be attributable to the Government's¹⁵ poor vigilance in monitoring and ensuring compliance of these social institutions to the stipulations of good governance.

Given that the responsibility of implementing the much-needed interventions rests on the society as a whole, there is considerable overlap in the specific tasks and roles of societal decision makers and gatekeepers across each of the social institutions. The chronological order in which the findings have been explicated is crucial to the appropriateness of the recommendations suggested in this thesis. In view of this, recommendations are suggested in light of each of the categories of *being different*. These recommendations stem from my knowledge of the sociocultural underpinnings of the Nigerian society.

Given that visual impairment is the first limitation for PWA right from birth even before they become integrated in the society, I contend that the provision of free [or affordable] eye care services right from an early stage would significantly increase their visual capacity. This responsibility rests on the Government to recognise albinism as a disability and to pull the necessary economic levers of equity that will ensure medical and social welfare for babies with albinism during developmental stages of growth. This interventional approach has the potential to achieve equality of accessing full learning participation for children with albinism alongside other children in the schooling environment during childhood, and by extension increase their capability for self-determination in order to access social goods throughout their life course.

¹⁵ 'Government' is referred to as 'State' when it is used in the context of a social institution

Religion and the practise of religious faith inform social behaviour in Nigeria (Aluko, 2015); my own moral philosophy is a testament to this notion. To a considerable extent, institutionalised religion through the practise of either the Christian or the Islamic faith influences the social and interactional transactions that occur within the typical Nigerian family (Green, 2011). Similarly, there is a significant continuous exchange of influence between religion, politics and governance in Nigeria (Eboh, 1984; Sampson, 2014). Thus, religion can be regarded as a nexus from which other relevant social institutions can appropriate interventions for PWA. Several participants in this study have acknowledged that having faith and engaging in church activities help them cope with the realities of *being different*, thereby highlighting the positive impact of religion as a potential facilitator of societal acceptance and inclusion. My point of view here is that the principles of love, equality and justice that the Christian and Islamic religions advocate can be embedded into the framework of inter-institutional interventions to effectively inspire parents to treat their children appropriately. If this strategy becomes adopted and actualised in every home, then perhaps, children with albinism (CWA) will never have to experience the disadvantaging realities of *being different* in the family home environment.

The responsibilities of addressing [and forestalling] the disadvantages and injustices that PWA are likely to suffer in the schooling environment rests on the State and Educational institutions in collaboration with the families of CWA. Principally, the State should implement actionable policies and allocate resources that would enable the educational sector to provide adequate learning support for CWA. In the same vein, the educational institutions should improve the capacity of school administrators and teachers with adequate training to enhance the provision of disability support. Presently, the concessions approved by the Federal Ministry of Education [FMOE] (2012) at the 58th National Council on Education allow CWA to be seated on the front row closer to the whiteboard, and for examiners to grant

them double and half of the original time during examinations. However, there is paucity of evidence to confirm the extent to which these concessions are implemented across the country and even if they are effective in improving equality and academic outcomes for CWA in the schooling environment. Recognisably, being seated on the front row in the classroom accentuates the visibility of CWA and makes them more conspicuous in the classroom which further increases the likelihood of *being an object of curiosity*. This implies additional responsibility for school administrators and teachers to remain vigilant in order to address occurrences of *being picked-on* and bullying. In addition, school curriculum at all levels should recurrently include topics on civic duties aimed at instilling patriotism as a sense of duty, fairness, disability awareness and tolerance, kindness, and service to humanity. This strategy will serve to promote the Ubuntu African philosophy of ‘being your brother’s keeper’ as a means to reorientate perceptions and drive positive social behaviour towards albinism and PWA. There is also the need for school administrators and teachers to collaborate with parents so that adequate support would be contiguously provided for CWA in and out of the schooling environment.

In order to ameliorate the realities of *suffering double tragedy* as adults, the Nigerian Government having enacted the 2018 Discrimination Against Persons with Disabilities (Prohibition) Act, should further monitor compliance of employers in the economic institutions. Eligible PWA should be appointed into positions of influence in the public and private sector so as to demonstrate to the society that they have capacity to work and participate in social development. The occurrences of negative relationship experiences may be alleviated by means of driving a positive change in social behaviour through publicly funded mass education and sensitisation on electronic and print media. In addition, appropriately structured religious sermons would also contribute to mass education and

sensitisation, and perhaps promote a culture of societal protection and respect for females with albinism.

The sum of these insights is that if the Nigerian society becomes appropriately re-configured, then, it is likely that the processes of *being different* would be altered such that PWA will begin to enjoy life more positively and productively.

9.4 Limitations of the study

Before presenting a summary of recommendations, it is worth acknowledging that this study is not without its limitations. Three limitations that have been identified in this study are:

1. Sample size
2. The scope of the study
3. Age restriction for participating in the study

9.4.1 Sample size

A reader of this thesis might contend that the small sample size poses a challenge to the generalisability of the findings in this study. However, the generalisability of a qualitative research such as this study should not be based on statistical measurements of probability sampling as is characteristic with quantitative research (Lewis, 2014). As argued by Smith (2018), the richness of a qualitative research can be located in a small but purposive sample size that offers theoretical insights into the defined scope of a phenomenon such as the social experiences of having albinism. Drawing on this argument, this study claims generalisability on three accounts.

Firstly, in consistence with the philosophical underpinnings of constructivist grounded theory, this study's ontological and epistemological assumptions about the relative knowledge of social realities and the methods of acquiring the knowledge of social realities

render the findings both useful and analytically generalisable regardless of the sample size (Kay, 2016). Secondly, the extent to which the extant theories of stigma and social justice have been adopted to explain the realities of *being different* affords the findings a claim to theoretical generalisability. Thirdly, given my personal encounters with PWA [as presented in Sections 3.2.1 and 8] that resonated with participants' experiences with regards to societal attitudes, the findings in this study can be considered to be naturalistically generalisable (Stake 1978, 1995).

Nevertheless, I acknowledge that the small number of participants may be attributable to any of the following three factors:

- (i) PWA in Nigeria are a group of people who believe the society has failed them despite several attempts to promote advocacy for social equity, equality and security. Sustained disappointment may have discouraged their participation in this study;
- (ii) all participants were recruited from only one point of contact, the Albino Foundation in the city of Abuja. I could not sample across different states and points of contact because of my limited financial resources being a self-sponsored international student bearing expensive tuition fees;
- (iii) also, time constraints due to the nature of this study being an academic requirement for a doctorate degree within a given timeframe meant I was the only one to conduct the research and that I could not tarry in the field longer than permitted by time and resources

9.4.2 Scope of the study

I recognise that *being different* only answers the research questions from the participants' point of view. The processes that constitute the theoretical construction would have

benefited from a larger scope of participants to include members of the society and their perception of albinism and PWA.

9.4.3 Age restriction for participating in the study

The age-specific sampling criterion required that only PWA aged eighteen years and above were eligible to participate in this study. This meant I could not capture childhood experiences of CWA in present time. As such, this study was only able to assess participants' childhood experiences retrospectively. Admittedly, sampling children would have required stringent ethical implications that the accorded time for the completion of the doctorate programme for an international student would not have been able to afford. Having identified these limitations, I acknowledge that these limitations necessitate the need for further research in terms of:

- Using a larger sample size to refine or extend the emerged theory of *being different*
- Conceptualising society's perceptions of albinism and PWA
- Refining childhood experiences of CWA by recruiting age-appropriate participants who are having real-time social experiences

9.5 Recommendations

In congruence with the framework of an integrated social model of disability as discussed in Section 7.6, Table 7 below illustrates the specific recommendations that have been suggested in this thesis.

Table 7: Recommendations

Recommendations			
Processes of <i>Being different</i>	Stage of life and context	Relevant social institution(s) ¹⁶	Specific roles and Suggestive strategy
Being different	<ul style="list-style-type: none"> Experienced throughout the life course of a PWA as a continuum of realities 	<ul style="list-style-type: none"> State Economy Religion Education Family 	<ul style="list-style-type: none"> State to establish policies that will enable and empower the health sector to diagnose albinism at birth; to register babies with albinism into a national register of disabilities and special needs; to offer free eye care services and prescription glasses to CWA at intervals during childhood and adolescence through the National Health Insurance Scheme (NHIS) State to partner with relevant economic institutions and development partners for public funding of disability care to reduce financial burden on the NHIS Eye care services may be subsidised for adults with albinism who are in employment or offered free to those who are unemployed State can drive positive social change and tolerance through collaborative effort with Educational

¹⁶ Social institutions include Family, Religion, Education, Economic and State. Economic encompasses the working environment. State encompasses the duties of the Government to provide and enforce fair and inclusive policies; medical and social security; and the rule of law and justice to ensure and protect citizens' rights and wellbeing

			institutions by leveraging on the influence of Religion and Family for the purpose of social mobilisation and societal reorientation at the grassroots and within the communities
Being in a tug of war	<ul style="list-style-type: none"> • Childhood • Family home environment 	<ul style="list-style-type: none"> • Family • Religion 	<ul style="list-style-type: none"> • Religious leaders in the Christian and Islamic faiths to mentor parents on upholding the principles of love, equality and justice amongst their children within the home • This may decrease the likelihood of negative parental treatment towards CWA • This way, no CWA will be disadvantaged at home
Disadvantaging schooling and social system	<ul style="list-style-type: none"> • Childhood and adolescence • Schooling environment 	<ul style="list-style-type: none"> • State • Education • Family 	<ul style="list-style-type: none"> • State to institute actionable policies of inclusion, and resource allocation for disability support to empower the educational institution. • State to monitor compliance • Educational sector to implement the policies, ensure vigilance and report on compliance; to improve school curriculum to reorientate social perception of disabilities and drive positive social behaviour • Educational sector to work with parents of CWA in collaborative provision of support
Suffering double tragedy	<ul style="list-style-type: none"> • Adulthood • Working environment • Social environment 	<ul style="list-style-type: none"> • State • Economy • Education 	<ul style="list-style-type: none"> • State to ensure vigilance and compliance to the Discrimination Against Persons with Disabilities (Prohibition) Act, 2018

		<ul style="list-style-type: none"> • Religion 	<ul style="list-style-type: none"> • Economic institutions to be more accessible to PWA for skills acquisition and entrepreneurial opportunities • Appointment of PWA into roles of importance in public service would be symbolic to demonstrate their capacity in the working and social environment • Mass education and sensitisation through radio, television and print media to dispel superstitions and negative social constructions of albinism and by extension discourage sexual exploitation of females with albinism • Religion by means of appropriate sermons and messages can influence positive social perceptions and behaviour within the social environment
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In keeping with my sense of duty and solidarity for the albinism cause, I intend sharing the findings of this study and suggested recommendations with the Albino Foundation. In addition, an initial step towards dissemination of knowledge in the academic space is to publish this study in the Journal of Vulnerable Children and Youth Studies

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Appendix A: Ethical Approval from Faculty of Health and Social Care

AM/bh

11th March 2016

Anthony Adeolu Olagunju
3 Denbigh Street
Chester
CH1 4HL



University of
Chester

Faculty of Health and Social Care

Tel 01244 512600
Fax 01244 511270

Dear Anthony

Ethical Approval Granted

FH&SC Ethics Number: RESC0116-671
Course of Study: PhD/Mphil
Supervisor: Dr. Andi Mabhala
Student Number: 1220673

I am pleased to inform you that the Research Ethics Sub Committee of the Faculty of Health and Social Care approved your project *"Albinism in Nigeria: life experiences and implications for health and wellbeing"* on 3rd March 2016.

Approval is subject to the above and following conditions:

1. That you provide a brief report for the sub-committee on the completion of your project.
2. That you inform the sub-committee of any substantive changes to the project.

We approve your application to go forward to the next stage of the approval process. If you are applying to IRAS and require a sponsorship letter and insurance documentation please contact Barbara Holliday.

If you have any questions or require any further assistance please contact Barbara Holliday on 01244 511117 or by email b.holliday@chester.ac.uk

Yours sincerely

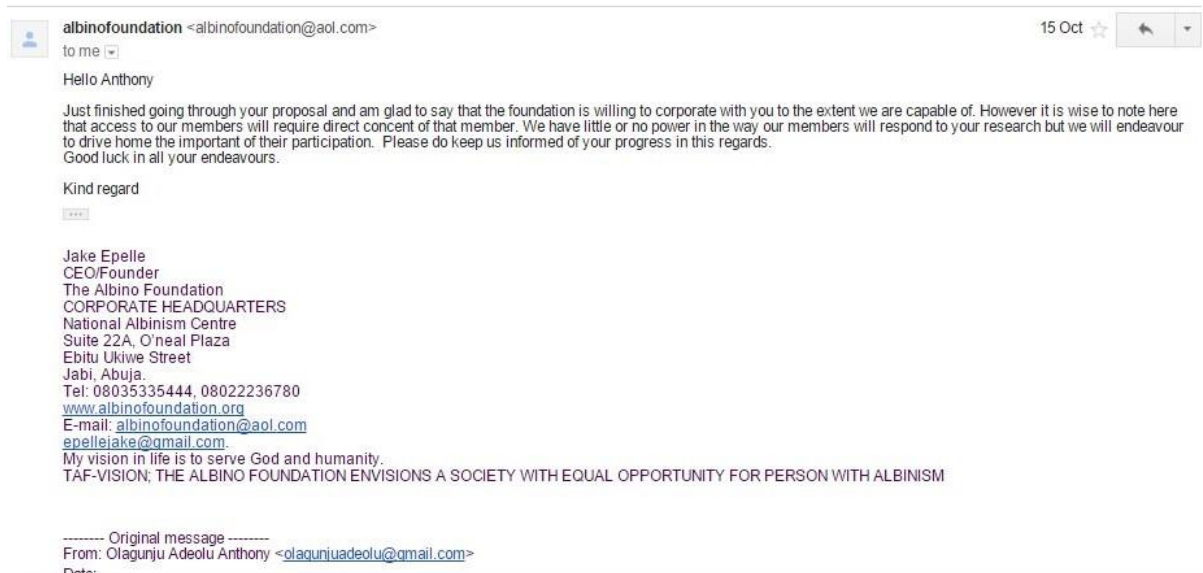
Dr. Andrew Mitchell
Chair, Faculty Research Ethics Sub-Committee

cc Research Knowledge Transfer Office
cc Academic Supervisor

University of Chester, Riverside, Castle Drive, Chester, CH1 1SL

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Appendix B: Approval from The Albino Foundation



Appendix C: Participant Information Sheet
Short title of study

Albinism in Nigeria: life experiences and implications for health and wellbeing

You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask **me** or **Ms. Oluchi Iwuoha, Assistant Program Specialist of The Albino Foundation** if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

Thank you for reading this.

What is the purpose of the study?

This study aims to explore your views of personal health and general wellbeing as a person with albinism living in Nigeria.

Why have I been chosen?

You have been chosen because you are a person with albinism

Do I have to take part?

It is up to you to decide whether or not to take part.

If you decide to take part you are free to withdraw without giving reasons any time during the process up until the point of data analysis or one month after the interview, whichever comes first.

A decision to withdraw, or a decision not to take part, will not affect the support you already enjoy from The Albino Foundation.

What will happen to me if I take part?

If you decide to take part, you will be given this information sheet to keep and asked to sign the consent form and keep a copy of that as well.

You will be invited to attend an interview session in one of the offices of The Albino Foundation.

At this session, you will have the opportunity to tell me your story and you will not be interrupted.

You and I would be the only people in the room.

The interview may last about an hour, depending on how much information you choose to share with me.

If you feel tired or distressed at any point during the interview, you are free to take a break, adjourn or terminate your participation.

You may be invited to come in and attend another interview session if there are important details from your story that I need clarity on; this would be arranged with your permission and at a convenient time for you.

With your consent, the interview(s) will be audio taped. This is solely for my data analysis and no one else will listen to the recording.

No one will be able to identify you because you will not have to mention your name.

What are the possible disadvantages and risks of taking part?

There may be times when you feel upset at recalling life events. Please remember that you are free to stop the interview at any time, and access counselling support from the Foundation.

What are the possible benefits of taking part?

By taking part, you will be contributing to the understanding of the challenges you are facing and the changes you would like to experience. The final report may provide information to the wider society leading to a better understanding of the challenges faced by Nigerians with Albinism in terms of health and wellbeing.

What if something goes wrong?

If you wish to complain or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact: Professor Annette McIntosh-Scott, Executive Dean, Faculty of Health and Social Care, University of Chester, Riverside Campus, Castle Drive, Chester, Cheshire, CH1 1SL. Tel: 01244 513380. Email: a.mcintosh@chester.ac.uk

If you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence (but not otherwise), then you may have grounds for legal action, but you may have to pay for this.

Will my taking part in the study be kept confidential?

All information collected about you during the course of the research will be kept strictly anonymous so that you will not be identifiable.

What will happen to the results of the research study?

The results will be written up into a thesis that I would present to my Faculty.

I intend to use the study to publish academic papers.

It is hoped that the findings may be used by The Albino Foundation to call for quick enforcement of the 2012 Disability Act.

You will not be identified in any subsequent report or publication.

Who is organising and funding the research?

I am funding this research with approval from my Faculty.

Who may I contact for further information?

If you would like more information about the research before you decide whether or not you would be willing to take part, please contact:

Anthony Adeolu Olagunju
1220673@chester.ac.uk

Thank you for your interest in this research.

Appendix D: Consent form

Title of Project:

Albinism in Nigeria: life experiences and implications for health and wellbeing

Name of Researcher: Anthony Adeolu Olagunju

Please
initial box

1. I have read and understood the participant information sheet and have had the chance to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time during the process up until the point of data analysis or one month after the interview ☐
3. I understand that with my permission the interview will be audio-recorded. ☐
4. I understand that the information I will give would be written up as part of a report and used in academic papers and that I will not be able to be identified in the documents ☐
5. I agree to take part in the above study. ☐

Name of Participant (pseudonym)

Date

Signature

Researcher

Date

Signature

Name of Person taking consent
(if different from researcher)

Date

Signature

Appendix E: Interview schedule

Albinism in Nigeria: life stories of albinos and conceptualisation of their social and health status

Opening

Exchange greeting [shakes hands]

Offer a cup of juice/tea/coffee/water

Reiterate the purpose of the study

Remind participant to read the participant information sheet and ask any questions

Obtain consent

Researcher to participant: With your permission, I would like to audio-record our interview for my reflection and analysis

Ask participant to give verbal consent by speaking into the Dictaphone

Remind participant that they are free to interrupt or terminate the interview if they feel the need to

Interview begins with:

Please could you tell me your life story of being an albino in Nigeria?

Probes:

How do you see yourself as a Nigerian?

Describe to me how it is being an albino within your family

Could you tell me the stories that reflect your feelings of being an albino at school?

Can you tell me about your experiences of accessing healthcare?

How does it feel to be an albino in your community?

Please tell me about your experiences with relationships

How does being an albino affect your work life?

Please tell me how you cope with being an albino

Interview ends

Thank you for sharing your story with me.

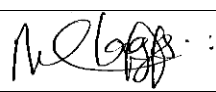
Is there any other thing you'd like to add?

I hope you will spare me some more of time in future because I may need you to elaborate on what you have shared with me today

In the meantime, if you remember and want to share additional details, please contact me and we will schedule another session

Thank you again and see you soon.

Appendix F: Risk Assessment/Distress Protocol

Assessment Undertaken By	Anthony Adeolu Olagunju			
Department / Location	Department of Public Health and Wellbeing			
Signed		Date	21/12/2015	
Hazards identified	Risk of, or from & who is at risk	Control measures already in place	Further Actions Required	Review Date
Male lone worker during the interviews (physical safety)	Risk of physical harm to researcher from lone working	The researcher will follow the University of Chester lone worker procedure guidance. All interviews will be conducted in the premises of The Albino Foundation within normal working hours	Procedure will be reviewed after each interview.	
Participant becomes upset when recalling life events	Risk of expression of upset by the participant to the researcher.	Participant can decide to speak with the Counsellor at The Albino Foundation	After calming down, participant would be able to decide if they wish to continue with interview, adjourn for another date or terminate participation	
Emotional safety of researcher	Risk of emotional stress to researcher from interview sessions	Researcher has the support of experienced supervisors in the UK and Nigeria for encouragement and morale-boosting		