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Albinism in Tanzanian Higher Education:
A Case Study

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Abstract

My thesis focuses on the experiences of people with albinism in higher education (HE) in Tanzania. Albinism is a genetically inherited condition and it affects people of all ethnic backgrounds worldwide. In Tanzania, the condition affects one in every 1,400 people. People with albinism in Tanzania often face social discrimination, superstition, and prejudice including murder threats due to myths and beliefs that their body parts are a source of wealth and prosperity. They also experience physical challenges including threats from the African tropical sun and visual impairment. All these factors interact with educational opportunities.

Information about the oppression, killings and amputation of body parts of people with albinism in Tanzania has been widely reported in the media globally. However, albinism remains socially under-researched and under-theorized – especially in relation to how it interacts with HE opportunity structures. This research attempts to contribute to existing literature and construct new insights into albinism and HE. In so doing, I draw upon a range of theoretical approaches including Sarah Ahmed's concept of affective economies and fear of difference, Margaret Archer's notions of the internal conversation and reflexivity as well as various established feminist theorists such as Simone de Beauvoir to analyse and explain issues arising from the study including misogyny. I also draw upon Pierre Bourdieu's concept of symbolic violence.

My research is a case study of albinism in HE in Tanzania. Using qualitative methods I draw upon feminist methodological approaches, values and principles to explore albinism and explain what constrains and enables students with the condition to interact with HE opportunities. The data for this research were collected from 35 participants in Tanzania, namely: 14 students with albinism (involving current and graduate students with albinism); six teaching staff and five HE support staff members. Other participants included officials from four non-governmental organisations (NGOs), four government officials, one parent and one student reader/note-taker. I conducted 19 face-to-face semi-structured interviews with six current students with albinism, three teaching staff, four NGO officials and four government officials. Likewise, I conducted face-to-face semi-structured interviews with one parent and one student reader. I also conducted one Skype interview with a current student with albinism as well as three focus groups discussions with 14 participants. The

first group was of seven graduates with albinism, the second involved three teaching staff and the third was of four HE support staff. I also used desk-based research methods, conducting telephone conversations with 52 statistics officers in order to investigate where students with albinism are located within HE in Tanzania. Looking at literature and my research questions, the data were then compared across different participants and universities to establish patterns and common themes among them.

The findings from this research indicated that the systems of power that work to oppress people with albinism are multifaceted with structural, cultural and socio-economic conditions. Some key findings included how people with albinism were subjected to misogyny, myths and fear of the 'other'. However, the 14 students with albinism in this study demonstrated a high level of agency, creativity, autonomy and motivation to improve their lives and thus overcome discriminatory social structures, oppression and harassment. They also illustrated their commitments to contribute usefully to society despite the constraints and limited support that they often encountered. Access to HE was seen as a major way to transform their identity by challenging deeply ingrained social prejudices, which often label people with albinism as having limited cognitive capacity. The implications of this research are that government commitment will be required in order to allocate sufficient funds to promote awareness of, and create change about, albinism and the elimination of household poverty, particularly that of female-headed households (FHH), as well as to adequately finance HE institutions so they can put in place support services and arrangements for students with albinism.

Dedication

I dedicate this thesis to people with albinism and mothers of children with albinism who bravely cope with harassment, abuse, discrimination and mistreatment. I also dedicate my thesis to my late mother, who gave birth to five girls but was seen as having no children.

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List of Acronyms

ACSEE	Advanced Certificate of Secondary School Education
Agri	Agriculture
BMA	Business Management and Administration
CEP	Cultural emergent properties
PhD	Doctor of Philosophy
Edu.arts	Education in arts subjects
Edu.sc	Education in science subjects
FHH	Female household headship
GER	Gross enrolment rate
HE	Higher education
HESLB	Higher Education Students' Loan Board
HSES	High socio-economic status
ILO	International Labour Organization
IMF	International Monetary Fund
LLB & Soc.sc	Law and social sciences
LHRC	Legal and Human Right Centre
LSES	Low socio-economic status
MA	Masters degree
Med.sc	Medical science
MSES	Middle socio-economic status
MOEVT	Ministry of Education and Vocational Training
NDS	National Disability Survey
NECTA	National Examination Council of Tanzania
NOAH	National Organization for Albinism and Hypopigmentation
Nat.sc	Natural sciences
NGO	Non-governmental Organisation
OA	Ocular albinism
OCA	Oculocutaneous albinism
OUT	Open University of Tanzania
CSSE	Ordinary Certificate of Secondary School Education
PEP	Personal emergent properties
PG	Postgraduate degree

RPL	Recognition of Prior Learning
STEM	Science, Technology, Engineering and Mathematics
SAPs	Structural Adjustment Policies
SSA	Sub-Saharan Africa
TCAIDS	Tanzania Commission for AIDS
TCU	Tanzania Commission for Universities
TEA	Tanzania Education Authority
TAMWA	Tanzania Media Women's Association
UG	Undergraduate
UTSS	Under The Same Sun
UPIAS	Union of the Physically Impaired Against Segregation
UK	United Kingdom
UN	United Nations
UNESCO	United Nations Education and Scientific Organisation
UNHRC	United Nations Human Right Council
URT	United Republic of Tanzania
USA	United States of America
UDSM	University of Dar es Salaam
WPHEGT	Widening Participation in Higher Education in Ghana and Tanzania
WHO	World Health Organization

Chapter One:

Introduction

1.1 Why this topic is important

My thesis focuses on students with albinism in higher education (HE) in Tanzania. People with albinism in Tanzania often face discrimination, superstition, social prejudice and threats from the hot and sunny tropical climate. They also face murder threats due to myths and beliefs that their body parts are a source of wealth and prosperity. Recently, a report by the United Nations Human Rights Council (UNHRC) revealed that there were a total of 340 attacks on people with albinism and 134 murders within 25 countries (2015: 5). The report also revealed that in Tanzania there were 151 attacks on people with albinism since 2000 of which 74 cases have been fatal. The attacks were listed as mutilation, violence and grievous bodily harm. All these factors interact with educational opportunities and challenge the widening HE participation agenda in Tanzania, which aims at promoting social inclusion.

Information about the oppression, killings and amputation of body parts of people with albinism in Tanzania has been widely reported globally (Hong et al, 2006; Luande, 2009; Lynch and Lund, 2011). Positive and negative albinism discourses have also circulated in international and local media (Soares, 2008; Associated Press, 2009; Chang and Diaz, 2010; Siyame, 2013; BBC News, 2015). However, albinism remains socially under-researched and under-theorised. This absence of academic interest is surprising, especially when one considers that such oppressive factors have not only been widely reported but that they can also constrain people with albinism's various social and economic opportunities.

I would like to make the point here that in Tanzania albinism is considered to be a disability. Disability is without doubt defined differently in different contexts. In the international context, disability is regarded on the one hand as a long-term physical, mental, intellectual or sensory impairment in which interaction with various barriers may hinder a person's full and effective participation in society on an equal basis with others (United Nation Convention, 61/106 2006). On the other, it relates to the end result of the interaction between an individual's health and the context in which that individual

lives (World Health Organization (WHO), 2001). Disability in the Tanzanian context is analysed as a social construct. It is viewed as a loss or limitation of opportunities to take part in the normal life of the community at an equal level with others due to physical, mental and social factors (United Republic of Tanzania (URT), 2004: i). In 2004, when Tanzania was developing its first national disability policy (NDP) because of persistent oppression, stigmatisation and ill-treatment, the community of people with albinism in Tanzania asked the government to categorise them as disabled people so that the policy could also address their particular issues. In Tanzania, the conditions now recognised as disabilities are hearing, visual, intellectual, speech, and mobility impairment as well as albinism (URT, 2004).

The purpose of this study is to engage with the existing literature on disability in HE, with particular reference to albinism in Tanzania. This thesis attempts to contribute to the existing literature and construct new insights on students with albinism in HE. Of course, students with albinism may have similar experiences to other disabled and non-traditional students in HE, given that they all face discrimination, prejudice and harassment (Barnes, 2007; Mumba, 2009; Fuller et al., 2010; Morley and Croft, 2011). However, there is a major difference between the experiences of students with albinism and that of other disadvantaged groups, namely, that superstitious beliefs encourage some people to hunt people with albinism for their body parts. Their experiences are thus both unique and more interesting to study, as it is important to know how they interact with HE opportunities.

1.2 Introducing my thesis

This chapter introduces my thesis. I discuss albinism, which was the unit of analysis, or case for my research. I briefly talk about what I did, where and with whom. I also engage with debates that have surrounded the concept of albinism. This is followed by definitions of terminologies that have been adopted in my thesis. Thereafter I reflect upon how I came to be interested in the topic of albinism in HE, and also explore my research journey and the aims of my research. I then provide some highlights about Tanzania, which is the country context of this research, and its education system, paying particular attention to HE. When discussing the Tanzanian education system, I attempt to answer my first sub-question, which asks the location of students with albinism within Tanzanian HE. This is followed by the structure of the thesis, and, finally, a discussion of the limitations of this research.

Given the low profile often assigned to disabled people, the *African Network on Evidence to Action on Disability* invited African researchers to disseminate success stories about disabled students in HE (Tuomi et al., 2015). My research on albinism in Tanzanian HE is therefore meant to contribute towards this end and enrich our understanding of disability, particularly albinism. In so doing, I hope to minimise the absence or misrecognition of students with albinism in HE literature in Tanzania, sub-Saharan Africa (SSA) and other parts of the world.

Another contribution that this thesis will make is to add to the study by Morley et al (2010) on *Widening Participation in Higher Education in Ghana and Tanzania: Developing an Equity Scorecard* (WPHEGT). This study focused mainly on three structures of inequality, namely gender, socio-economic structure and age. Given that disability as a structure of inequality was not one of the key focuses in the WPHEGT study (but did appear in the findings as an area of concern (Morley and Croft, 2011), my research will add to this study by including the experiences of disability in HE with a specific focus on students with albinism. As elaborated in my abstract, in studying the experiences of students with albinism in HE I conducted telephone conversations with statistics officers from 52 universities. I also collected data from eight groups of participants, comprising a total of 35 people, namely, 14 students with albinism, six teaching staff and five HE support staff. Other respondents were four NGO officials, four government officials, one parent and one student reader. The information about the 35 participants is provided in Tables Nos. 1 to 8. A detailed vignette showing their particulars is presented as Appendix I. In order to maintain anonymity, each participant has been assigned a fictitious name.

My justification for selecting the eight different groups of participants was that they provided varying perspectives on albinism in HE, given that my intention in collecting data from students with albinism was to understand better the experiences of albinism in HE from the students' own point of view. Archer tells us that 'someone who knows herself knows a good deal about it, some of which will be known to her alone' (2003: 19). This view suggests that, to a large extent, no one knows the experiences of students with albinism in HE better than the students with the condition themselves, and that some of those experiences are known to them alone. This way, the data from students with albinism was useful in illuminating their real experiences of interacting with HE opportunities and consequent participation in HE.

Morley et al., (2010) inform us that, in most cases, interventions carried out to widen participation focus on increasing enrolment, and pay less attention to strategies aimed at retaining students and enabling them to complete their studies. My choice to include graduates with albinism group was based on the need to address this limitation, given that the intention of this research was to understand the retention and completion strategies which exist in Tanzanian HE. The best group to provide such an understanding was, naturally, the one whose members had successfully completed and graduated from HE, who in this research are also referred to as students with albinism. This group had attended and graduated from five different universities.

I believe that teaching and support staff and students are a rich source of knowledge concerning the social and academic participation of students with albinism in HE spaces and practices. By involving the group that comprised teaching staff, support staff and a student reader, I was able to capture such knowledge by investigating their beliefs and the systems they practise, which can constrain or support students with albinism in HE. As to the government and NGO respondents, my official intention in involving these groups was to capture policy issues; another, however, was to understand the support that is available to students with the condition from both the government and NGOs.

The literature that focuses on the motivations or aspirations of disadvantaged groups and the families of disadvantaged groups widely sees the non-participation of these groups in HE as connected to the culture of the parents (Bauman, 2005; Demie and Lewis, 2010). They blame the lifestyle and lack of aspiration of the disadvantaged groups for their non-participation in education. While this type of blame is basically directed towards working-class parents, parents of other disadvantaged groups such as disabled children, including children with albinism, can be similarly blamed. For this reason, I decided to involve a mother of children with albinism in this research, so that I could better explore the support parents of students with albinism can offer, as well as the constraints they are under, in supporting their children's participation in HE.

Having discussed why I involved certain groups in this research, I will present the relevant information about the 35 participants in table form. However, it is important that before doing so I clarify how HE subject areas in Tanzania are classified given that, in order to protect the identity of the 14 students with albinism, I present their data by subject

area rather than by the programmes they were undertaking. Mentioning the programmes would result in easy identification. I have therefore clustered the programmes which they attended based on the Tanzanian method of classification. In Tanzania, HE programmes are clustered into eight subject areas (Tanzania Commission for Universities (TCU, 2013). These subject areas are agriculture (Agri), business management and administration (BMA), education arts (Edu. arts) and education science (Edu. Sc). Others are law and social sciences (LLB & Soc. Sc), medical sciences (Med. Sc), natural sciences (Nat. Sc) and Science, Technology, Engineering and Mathematics, which are often abbreviated as STEM (TCU, 2013).

In describing my participants, I also find it important to classify them in five age groups, namely 17 – 25 years, 26 – 36 years, 37 – 47 years, 48 – 58 years and 59 – 69 years. Likewise, I also describe my participants in terms of their different levels of study, these being undergraduate (UG), Masters (MA) and Doctor of Philosophy (PhD) programmes. To ensure anonymity, I refer to MA or PhD programmes as postgraduate programmes (PG).

Given that I have also identified the 14 students with albinism by their socio-economic status, it is essential to explain how this status is defined in Tanzania. In Tanzania, the population is classified in terms of class, this being divided into low socio-economic status (LSES), middle socio-economic status (MSES) and high socio-economic status (HSES) (World Bank, 2011). These classifications are based on the level of an individual's education, her or his access to health, the occupation of an individual household, and the assets an individual possesses (World Bank, 2011). From such classifications, the World Bank (2011) classify 85% of the Tanzania population as being under the low social economic class, 12% as middle class and 1% as high-class. However, in determining those students considered to be in need and therefore eligible for loans, the Higher Education Students Loan Board (HESLB), (2014) categorises students in terms of their parents' education and employment status as well as the school they attended. In this research, I consider the parents' education level and employment status in classifying the 14 students with albinism within the three economic status groups described above.

Despite such class stratifications, it is sometimes difficult to establish a person's, in particular a student's, class position. This is mainly because of the practised culture in

Tanzania, where some students depend financially on close relatives such as siblings, aunties, uncles, grandparents and so on. However, going by the stratifications which I elaborate above, I would say that except for the three students with albinism, who have MSES by Tanzanian standards, the rest of the 14 students with albinism participants, who are first generation HE students, fall into the category of LSES.

Having explained how I grouped my participants, I now present the details of the participants.

Table 1. Information about students with albinism sex, programme and level of study, age, type of universities and its location and socio-economic and student loan status

Name	Sex	Age group	Type of university and location	Subject area	Level of education	Socio-economic status	Loan status
Sarah	F	26 – 36	Public Urban	LLB & Soc.sc	UG	LSES	Yes
Grace	F	17 – 25	Public Urban	BMA	UG	LSES	Yes
Thomas	M	37 – 47	Public Urban	Edu.arts	PG	LSES	Yes
Angel	F	17 – 25	Public Urban	LLB & Soc.sc	UG	LSES	Yes
Simon	M	37 – 47	Private Rural	Edu.arts	UG	LSES	Yes
Loveness	F	17 – 25	Public Urban	Med.sc	UG	MSES	No
John	M	37 – 47	Public Urban	LLB & Soc.sc	PG	MSES	No

Table 2. Information about graduates with albinisms' sex, programme of study, age, type of universities and its location and socio-economic and student loan status

Name	Sex	Age group	Type of university and location	Subject area	Level of education	Socio-economic status	Loan status
Meshack	M	26 – 36	Private Urban	Edu.sc	UG	LSES	Yes
Happiness	F	26 – 36	Private Urban	LLB & Soc. Sc	UG	LSES	Yes
David	M	26 – 36	Public Urban	LLB & Soc.sc	UG	LSES	Yes
Peter	M	48 – 58	Public Urban	LLB & Soc.sc	UG	LSES	Yes
Isaack	M	37 – 47	Public Urban	LLB & Soc.sc	UG	LSES	Yes
Lucas	M	37 – 47	Public Urban	BMA	UG	MSES	Yes
Deborah	F	26 – 36	Public Urban	LLB& Soc.sc	UG	LSES	No

Table 3. Information about teaching staff: sex, age, institutions and subject areas taught

Name	Sex	Age	Type of institution	Subject area taught
Joshua	M	48 – 58	Public	BMA
Elizabeth	F	59 – 69	Public	Edu.arts
Ruth	F	48 – 58	Public	Edu.arts
Steven	M	48 – 58	Private	Edu.arts
Yeremia	M	48 – 58	Private	Edu.arts
Azaria	F	48 – 58	Private	Edu.arts

Table 4. Information about HE support staff: sex, age, type of institutions and speciality

Name	Sex	Age	Type of institution	Speciality
James	M	37 – 47	Public	Sign language interpretation
Paul	M	48 – 58	Public	Braille reading & writing
Titus	M	48 – 58	Public	Braille reading & writing
Timothy	M	48 – 58	Public	Braille reading & writing
Julius	M	37 – 47	Private	None

Table 5. Information about NGO officials: sex, age, and condition

Name	Sex	Age	Has albinism
Ester	F	48 – 58	No
Abraham	M	48 – 58	Yes
Michael	M	37 – 47	No
Philemon	M	48 – 58	Yes

Table 6. Information about Government officials: sex, age, and area of duties

Name	Sex	Age	Area of duty
Joel	M	37 – 47	Government institution – HE
Elias	M	48 – 58	Government ministry – Policy
Samwel	M	48 – 58	Government ministry – special needs
Daniel	M	48 – 58	Government ministry – HE

Table 7. Information about a student reader: sex, age, type of institutions, subject areas, and levels of education.

Name	Sex	Age group	Type of university	Subject area	Level of Edu
Mary	F	26 – 36	Public	BMA	UG

Table 8. Information about a mother of children with albinism: age, level of education, socio-economic status

Name	Age group	Level of education	Socio-economic status
Eliza	59 – 69	HE	MSES

Having described the 35 participants of this research, I return to my earlier discussion of feminist research and its contribution to feminist literature. As feminist literature criticises the absence of women from minority groups in feminist works (Mohanty, 1988; Spivak, 1988; Abu-Lughod, 2006), my thesis will contribute towards rectifying this absence by putting forward the experiences of women with albinism in HE and discussing the experiences of mothers of children with albinism in Tanzania in relation to their children's participation in education.

Stimulated by the limitations in the academic literature and by my personal interest in disability in HE in SSA, this in-depth case study research explores disability in HE using students with albinism in HE as specific cases to illustrate the factors which contribute to the success of disabled students studying HE in Tanzania. I investigated the constraints that they have had to overcome and the opportunities they have been able to create for themselves or been able to take advantage of. This case study research conducted in Tanzania draws upon qualitative methods of investigation, and, as mentioned above, its subject is albinism. Creswell (2013) sees a good qualitative research as that which reports from multiple perspectives. I therefore used multiple sources to understand better the participation of students with albinism in HE from eight different perspectives, namely those of HE students and graduates, teaching staff and support staff, along with those of NGO officials, government officials, a student reader and a parent. I conducted 19 semi-structured face-to-face interviews and one Skype interview, and held discussions with three focus groups and a desk-based research. These methods of data collection provided a space for the silenced voices of people with albinism to be heard and listened to.

Nielsen (1990) tells us that researchers often carry their worldviews, emotions and personal experiences in the research topic they choose. I am no exception. I am a woman from a society which is mostly patriarchal, and have thus experienced various social and cultural constraints in my interaction with HE opportunities. The general aim of my research was

to develop a better understanding of the experiences of students with albinism who are also a vulnerable group, in terms of their interaction with HE opportunities. My interest was in the constraints and enablers that influenced their participation in HE. More specifically, my research attempts to address one key question: ‘What are the experiences of students with albinism in interacting with HE opportunities in Tanzania?’ (For example, access, retention, completion, achievement and support of students with albinism, as well as their motivation for undertaking HE). Within this overarching question, the following questions are detailed:

1. Where are students with albinism located in HE in Tanzania?
2. What are the barriers and enablers to their participation in HE, e.g., support from teachers, families, and communities?
3. What are the motivations for students with albinism to enter HE?
4. What are the life experiences of inclusion/exclusion in different phases of education?
5. What are their academic HE experiences, e.g., of teaching and learning, assessment and learning support?
6. What specific support is in place for students with albinism?
7. What needs to be done differently to enhance the participation and achievement of students with albinism in Tanzanian HE?

These research questions are informed by my theoretical framework, which draws upon several theoretical approaches, including Ahmed’s (2000; 2004a; 2004b) notion of affect and fear of difference; Bourdieu’s (1984; 2001) concept of symbolic violence; the notion of misogyny conceptualised by various established feminist theorists including de Beauvoir (2011 [1949]); and Archer’s (2000; 2003) notion of the internal conversation and reflexivity. Affective economies, fear of difference, symbolic violence and misogyny concepts are employed to clarify those of my research questions which require answers as to factors which constrain the participation of students with albinism in HE, whereas the internal conversations and reflexivity notions provide this research with answers as to the factors which enable students with albinism to interact with HE opportunities.

As indicated above, my research focused on a group that is often subjected to oppression and mistreatment. My interest was in listening to the voices of people with albinism, particularly women with albinism that have often been silenced. I believed that in order

to adequately listen to such voices I needed a strong feminist commitment (Renzetti, 1997; Oakley, 2000). Feminism, I believe, accords respect and recognition of difference in my research. It also respects the role of the researcher because my intention was not to oppress further the participants who took part in my research. In this way I draw upon feminist values and principles such as acknowledging the significance of gender in social life, respecting participants, acknowledging difference and aiming for research that is non-exploitative and thus minimises power imbalances (Wilkinson and Morton, 2007). These values and principles have much to offer because of my interest in gender and power relations, as well as in exploring the forces that maintain and sustain the domination of people with albinism and, in particular, women with albinism. At this point I look at disability and poverty.

1.3 Disability and poverty

Falkingham and Namazie, in their 2002 report for the British Government's Department for International Development, see poverty as multi-dimensional. They define poverty as 'a phenomenon that does not only encompass the lack of material consumption or resources but also involves the psychological pain of being poor, low achievement in education and health, and a sense of vulnerability to external events' (2002: 7). Although the World Bank (2015b) now agrees with the growing notion that poverty is a multi-dimensional phenomenon, it continues to measure universal poverty in monetary terms. For this reason, it draws the extreme poverty line at less than US \$1.25 (equivalent of UK 0.80p) per person per day (World Bank, 2015b).

Going by both Falkingham and Namazie's (2002) definition of poverty and the World Bank's (2015a) poverty line, my research suggests that disabled people in Tanzania, including those living with albinism, live in poverty. This is because of their limited material resources and educational opportunities as well as the continuing oppression that they often experience. In Tanzania, for example, 88.2 per cent of disabled children do not attend school because of poverty (National Disability Survey (NDS), 2008). Similarly, 47.6 per cent of disabled people were found to be illiterate as compared to 25.3 per cent of those without disability, and only four out of 10 disabled children aged seven to 13 attended primary education (NDS, 2008). Furthermore, according to NDS (2008), only five per cent of disabled students proceed to secondary school and fewer than one per

cent enters HE. This means that 99 per cent of disabled people do not interact with HE opportunities due to poverty. Given that HE is well documented as being an important mechanism in minimising individual poverty, it is important that we know what support is available to people with albinism in order to allow them to fully participate in it. Sub-question number six of this research aims to provide this knowledge.

In relation to specific data on students with albinism, a study on accessibility to education for children with disability in Tanzanian schools by Haki Elimu (2008), which is a NGO dealing with the educational rights of children in Tanzania, revealed that a high number of children with albinism were not participating in education. The study, which was conducted in seven districts of Tanzania, reveal that in the two districts out of the seven districts under study there were a total 178 children with albinism and out of these children 103 children were out of school due to various reasons including poverty. Likewise in Malawi, a study, which looked at the education of children and young people with albinism, found that some of them could not attend school because of poverty (Lynch and Lund, 2011). Poverty, therefore, can limit the chances of students with albinism to acquire the necessary qualifications to interact with HE opportunities, thereby increasing the risk that they will continue to live in poverty.

Given the potential of HE to relieve individuals from poverty, as well as to offer its graduates a positive outlook, (Bloom et al., 2006; UNESCO, 2012; Morley et al., 2010; Morley and Croft, 2011; Brennan and Durazzi, 2013), the purpose of this study is to understand better what constrains or enables the participation of students with albinism in HE. This understanding is important because ‘the acquisition of higher qualifications can reduce exclusion and maximize opportunities for inclusion in civil society and employment and provide financial independence’ (Morley and Croft, 2011: 384). The challenges that people with albinism in Tanzania experience are enormous and sometimes it is not easy to comprehend how some of them have negotiated participation in HE at all. It is therefore important to understand what constrains or enables the interaction of students with albinism with HE opportunities, as these barriers or supports need to be respectively removed or encouraged.

Despite the widespread potential of HE and the importance that some disabled people accord it, the literature on disability in HE in Tanzania indicates that disabled people,

including people with albinism, do not get equal access to education, particularly HE (Possi, 1996; Morley and Croft, 2011; Mwaipopo, 2011, Tuomi, 2014). Although the literature showed that to a certain extent disabled children might participate at primary school level, this participation decreases at secondary school level, limiting the pool, which enters HE (Possi, 1996; Morley and Croft, 2011; Mwaipopo, 2011). As a result of this, of the 55,314 students enrolled in Tanzania's HE institutions in the 2005/6 academic year, only 54 were disabled (Mwaipopo et al., 2011) and, as mentioned above, only one per cent of disabled students access HE. I now look at albinism.

1.4 A closer look at albinism

Albinism originates from the word 'albino'. The origin of this word has been much disputed. Some literature indicates that the name 'albino' derives from the Latin word 'albus', meaning 'white' (The National Organization for Albinism and Hypopigmentation (NOAH), 2002). Another notion is that 'albinism' derives from the word 'Albania' and is thus taken from the name of that country (Froggatt, 1960). The former theory traces the word 'albino' from the Greek word 'leukoethrope' or 'leukoethiopian', which means 'white Ethiopian' (Martin, 2002). In the 17th century, for example, the notion was that people with albinism were a race among the black population of Ethiopia (Froggatt, 1960; Ortonne et al., 1983 cited in Martin, 2002), which frames albinism within the context of races. However, the word 'albino' was also attached to Albania when the Greek writer Isogonus of Nicaea visited that country and came across people with features common amongst people with albinism (Froggatt, 1960). The claim here is that the similarities in the names might suggest that the word 'albino' was used to signify an occupant of Albania (Froggatt, 1960). Those who framed albinism within a country context insist that before the word 'albino' came into use, people with albinism were referred to as 'Albians' (for men) and 'Albanes' (for women), thus emphasising that the name denoted inhabitants of Albania, quoting the writings of ancient historians such as, Rackham (1942) and Rolfe (1948) (Froggatt, 1960).

The ancient literature (Rackham, 1942; Rolfe, 1948 cited in Froggatt, 1960) analysed and translated Isogonus' writings and their translations. According to Froggatt (1960), the literature indicated that Isogonus of Nicaea had seen people in Albania whose description resembles that of people with albinism, and therefore referred to such people as 'albinos'.

Nevertheless, debates about the origin and the meaning of the word ‘albino’ are ongoing which may be why the major languages of English, French, and German took so long to adopt the word. Froggatt (1960), who widely researched the historical perspectives of albinism, suggested that the word ‘albino’ was adopted into the three languages in the 19th century. Even when they did adopt the word, Froggatt (1960) says the word was principally designed for men with albinism whereas women were known as *albiness*. The word *albiness* is no longer in use and seems it has vanished from the world’s vocabulary, as women with albinism are now defined in relation to the word earlier only meant for men with albinism.

Currently, the term ‘people with albinism’ is widely used. It also seems that such a term is widely acceptable as a terminology of addressing or identifying those with albinism. Priestley (2001) made a useful distinction between two commonly disputed disability terms: the ‘people first language’ and ‘social model thinking’. According to Priestley (2001), the classification ‘people first language’, widely used by scholars from the United States of America (USA), increases the popularity of people by placing people first and uses terms such as ‘persons with disabilities’, whereas the ‘social model thinking’ common in the United Kingdom (UK), uses the term ‘disabled people’ as it recognises that people are disabled by society. Despite the contrast in terminologies, the term ‘person with albinism’ is widely used even in the UK. For example, Roy and Spinks (2005) UK scholars use the term ‘person with albinism’ in their book discussing the personal perspectives of people with albinism in the UK.

Likewise, British scholars such as Lund (2000; 2001; 2008) and Lynch and Lund (2011) who have researched and written widely about albinism in Malawi, Zimbabwe and South Africa also use the term ‘person with albinism’. Furthermore, Emma Burstall, a British journalist, in her article on the experiences of a couple with albinism in the UK which appeared in the *Saturday Guardian* ‘Family’ section (Burstall, 2012), also uses the term ‘people with albinism’ throughout the article. In relation to my thesis I use the ‘people first language’, which is ‘people with albinism’ when referring to those with albinism. The rationale for this was because that was how the people with albinism who took part in my research wanted to be identified. However, I have drawn upon the social model terminology when referring to disabled people in general. The rationale behind this is

that my study was written and examined in Britain where the term ‘disabled people’ originated and is widely used.

Returning to my discussion of albinism debates, the early literature also discussed albinism in historical terms; very little was scientifically known about its cause. It was not until the 19th century that the cause of albinism was scientifically confirmed, became the subject of scientific explanation and discussions and thus began to obtain a scientific meaning. Thus Albinism is now scientifically understood as a lack of melanin, which produces colour pigmentation. It is now known to be a genetic condition deriving from both parents carrying an albinism gene that does not produce melanin pigmentation (Hong et al., 2006; Luande, 2009). Despite both parents being responsible for the birth of a child with albinism, the literature widely reveals that mothers were blamed and accused of adultery for having children with albinism (Ntinda, 2009; Baker et al., 2010; Allen, 2011; Lynch and Lund, 2011). This is discussed in detail in Chapter Five. Even though the cause of albinism is now scientifically proven, globally, people with albinism have been found to experience discrimination and bio-psycho-social challenges (Burstall, 2012; Priestley, 2001; Westhoff, 1993; Ezello, 1989; Brody, 1981). In the UK and other parts of the Global North, for example, although there is more support and understanding of albinism and better technology to help people with albinism, people with albinism still sometimes attract unhelpful stares or sometimes name-calling (Burstall, 2012).

With scientific development, medical literature now reveals two types of albinism: *oculocutaneous* albinism (OCA), which results in lack of pigment in the eyes, hair and skin; and *ocular* albinism (OA), which results in lack of pigment only in the eyes (Luande, 2009; Baker et al., 2010; Lynch and Lund, 2011; NOAH, 2015). These two types of albinism make those living with the condition a heterogeneous group. My thesis therefore focuses on people with albinism in HE who have OCA, which, according to Luande (2009), is more common in Tanzania.

Albinism is a global phenomenon which affects people of all ethnic backgrounds. In Tanzania, official data on albinism is inconsistent and sometimes differs from one organisation to another. The absence of reliable albinism data can mean that people with albinism are often omitted from government plans and policies. However, the albinism prevalence rate in Tanzania is estimated at one in every 1,400 people and it is believed

that one in 19 people carry the gene (UTSS, 2013). Worldwide, its frequency rate is estimated to be one in every 17,000 people (Lapidos, 2009; Lund, 2000; Roy and Spinks, 2005; Burstall, 2012). Nonetheless, its prevalence rate varies extensively by population and is considerably higher in people of SSA descent. The prevalence of OCA in Africa is estimated to be one in every 8,500 individuals. In South Africa, the frequency rate is estimated at one in every 4000 people (Hong et al., 2006; Barker et al., 2010). In countries like Zimbabwe and Namibia, the frequency rate is much higher with a rate of one in every 1,000 people and one in every 3,000 people respectively (Ntinda, 2009; Lynch and Lund, 2011). High incidences of albinism are also notable in the Native American Kuna and Zuni in Panama as well as among people in the Dominican Republic and Japan (NOAH, 2002). Recent writings have indicated that the UK has an albinism prevalence rate of one in every 17-22,000 people (Burstall, 2012).

Albinism manifests itself in two conditions, which carry significant risks of impairment. The first is the lack of melanin pigment that helps in the blocking of ultraviolet radiation from the sun. This condition increases the risk of skin cancer and other related problems, particularly for those people living in tropical African countries such as Tanzania (Luande, 2009) where the level of ultraviolet radiation from the hot sun is high. The second albinism condition, as elaborated by Luande (2009) is that the eyes of people with albinism are often connected quite differently to the brain, affecting their vision and causing some to experience involuntary eye movements and most to have poor vision. Such experiences, when coupled with the harassment, prejudice, dehumanisation and discrimination that people with albinism often encounter, can mean that their disability is a result of their impairment and social constraints, thus suggesting what Shakespeare (2014) refers to as an interaction model of disability, which I explain in Chapter Two.

Despite a scientific explanation for albinism, in Africa, including Tanzania, people with albinism are often feared and hated (Lund, 2008; Baker et al., 2010; Lynch and Lund, 2011). However, Brocco (2015), who recently conducted a study in Tanzania, found that although people with albinism were still seen as the result of parents' misdeeds, particularly the misdeeds of mothers, these beliefs were changing and they were beginning to be seen as a result of God's will. Brocco's (2015) findings are an indication that people with albinism are beginning to be included and accepted by families and societies. Brocco (2015) relates the inclusion and acceptance of people with albinism with human

rights views which were promoted by international organisations. Thus pointing to the importance of advocacy in the inclusion of people with albinism in the society and in HE. Having looked at albinism, I will now discuss my own interest in the topic of albinism.

1.5 My interest and personal journey in exploring oppression

My initial interest in the topic of my research grew out of my working experience with HE students. I worked at a government regulatory organisation, which was responsible for overseeing university education in Tanzania. My work was to coordinate students' admissions into HE institutions. This work gave me an opportunity to meet and have official, or sometimes private conversations, with various students who were either in, or aspiring to enter, HE. One such conversation, which made an impression on me such that I still recall it, and which has influenced my research agenda, is that which I had with two disabled students in mid-2009.

The conversation was a narrative from two students as to how their friend, who was also a disabled student at one of the universities in Tanzania, had committed suicide because of harassment and stigmatisation experienced during HE. A significant message stood out from the two disabled students' conversation: that oppression and discrimination existed and were threatening and affecting their learning and life dreams. Since then I have been eager to explore the lived experiences of disabled people in HE and to better understand their interaction with HE opportunities because I knew that a study like this was essential, particularly from the feminist perspective of oppression. Thanks to a World Bank scholarship, the opportunity to study for my Doctor of Philosophy (PhD) at the University of Sussex came my way at the right moment, and I did not need to think twice about my research topic.

My PhD agenda has been for me a personal journey in ways that I could not have predicted. This journey has not only enabled me to better understand the life experiences of students with albinism, but it has also given me a new insight into my own life. Here I have become aware that as a woman, I have often been subjected to almost similar types of oppression and dehumanisation as those experienced by most people with albinism. I have learnt that women, just like people with albinism, are all measured against a 'normative' standard body and also share some common experiences of subordination and exclusion (Holland

and Ramazanoglu, 2002). Likewise, I became aware that we (women and people with albinism) are all sometimes defined as evil, dangerous, ungovernable, helpless, dependent, weak, vulnerable and incapable (de Beauvoir, 2011[1949]; Garland-Thomson, 2001). Of course, I do agree that people experience oppression differently and that therefore it has different effects on people (Anderson, 2005). However, in some cases groups can share experiences in such a way that they recognise themselves in the experiences of others and can thus speak of common experiences (Stanley and Wise, 1990). In this context, as a woman, it is possible to recognise myself in people with albinism's experiences of discrimination, abuse and harassment. Likewise, people with albinism can recognise themselves in the experiences of women (Stanley and Wise, 1990).

A British scholar, Morley (1992), tells us that we can internalise oppression and that internalised oppression can feed us with a sense of failure (Morley, 1992). Looking back now, I realise that the words, myths, pictures and discourses that I have frequently heard and seen about women must have impacted on me. Internalised oppression, as I realise now, did not only hold me back in public places but also in my writing. I recall how I had to struggle to put my voice into my study. I only succeeded after several attempts and attending various creative and academic writing courses. My journey, therefore, has not only deepened my understanding of the socio-cultural structures that restrict and enable the successful educational participation of students with albinism, but has also enriched my understanding of such structures in my own life.

My new understanding of existing barriers that can affect peoples' success challenged my early assumptions of agency. When I began this research, I anticipated finding confirmation of only agency in the life experiences of students in this research. But as I began my fieldwork, data analysis and writing, I began to realise that things were not as I had assumed. I realised that by assuming agency alone, I was missing out important aspects in the social lives of students with albinism. Archer (1995) reminded me that people are shaped by society and they also shape it. This new understanding meant a shift in my perspective. It therefore followed that I did not only search for agency in the life experiences of the 14 participants with albinism but also their social and cultural structures.

Given the complexity in exploring the life experiences of students with albinism, I felt that no single theory could adequately explain their experiences and therefore drew upon various theories. The first was Sara Ahmed's (2000; 2004; 2012) notions of affective economies and fear of difference, which I use to explain the boundaries that exist between those without albinism and those with albinism. The second was Pierre Bourdieu's (1984) concept of symbolic violence I used to explore the nuances of dominance in the students with albinism's life. Thirdly, I draw upon feminist theories, including that of Simone de Beauvoir (2011[1949]) and other prominent feminists, to analyse misogyny, which is a theme that also emerges from my data. Lastly, I draw upon Archer's (2000) theory of morphogenesis and notion of reflexivity to explain the structures and agency in the lives of students with albinism. These concepts are explained, and their relation to each other is discussed, in the respective analysis chapters, which are Chapters Four, Five and Six.

Albinism is surrounded by myths and superstitious beliefs in most SSA countries, including Tanzania, and myths and superstitions can influence peoples' perspectives and behaviours. In his book *Introducing Anthropology of Religion*, Eller (2007) sees myths as stories which influence peoples' perspectives, practices and behaviours. Eller (2007) thus believes that myths can sometimes be formulated by religious beliefs. For this reason, I believe it is important to examine African traditional religious beliefs and practices to understand better their link with the superstitious beliefs and myths which can circulate fear and hatred of albinism.

1.6 African traditional beliefs and practices

Africa is a large continent composed of fifty-two countries which have different cultures and whose people speak different languages and dialects. The fifty-two countries were under seven different colonial rules, namely those of Britain, Germany, Spain and Portugal, Italy, France and Belgium. As a consequence of seven different colonial regimes and an Arabic influence, Africa has become a fragmented continent with different administrative, governing and educational systems as well as foreign languages and religions such as Christianity and Islam.

Nyerere (2000) believed that before colonisation, African societies practised communitarianism. To him, 'Africans could not think of themselves outside the

community to which they belong' (Nyerere, 2000: 13). Likewise, Udo (2008) pinpoints that in African traditions and languages 'there is no 'me' but 'us', no 'my' but 'our' (p.95), thus emphasising the notion of communitarianism in African traditions. In the same spirit, Rodney (2011) believes that before colonialism, social relations and cultures in Africa were dominated by systems of communalism in which extended families and kinships were given primacy.

Cohen (2011) says that peoples' cultures are widely composed of shared beliefs, habits and customs and that such cultural components often originate from religions. This can therefore mean that communitarianism in ancient Africa might have originated from ancient African religions, especially when African scholars (Mbiti, 1989; Awolalu, 1976a) tell us that African traditional religions were gender-free. Their argument here is that women and men in traditional Africa could take up any of the three authoritative positions often given religious prominence, namely priesthood, diviners and traditional healers. Gender-free religions can imply the transmission of cultural habits and customs in which social groups, including women, are considered to be part of the community.

African traditional religions, according to Ikeora, are 'indigenous beliefs and practices of Africans' (2016: 12). This means that indigenous religions existed prior to the introduction of Christianity and Islam to Africa. As of 1900, for example, when Christianity and Islam were beginning to spread in sub-Saharan Africa, 76 per cent of the population was still practising traditional religions (World Religion Database, cited by PEW Research Center, 2010: p.i). These statistics imply that a large number of Africans had indigenous ways of living, believing and worshipping.

Worshipping in indigenous religions, according to Awolalu (1976a) and Mbiti (1989) is largely based on deities, ancestors and spirits while beliefs are widely in supernatural powers (magic/witchcraft). For this reason, believers are expected to pray, and make oaths, to deities, ancestors and spirits. The oaths are usually that the followers will abide by the norms, taboos, values and guiding principles of the religion in question. I have personal experience of this, as both my paternal and maternal grandparents were followers of traditional religions although my parents were Christians. My parents converted to Christianity at a very young age with the full approval of their parents. Although my parents were allowed to convert to Christianity, their parents could not forego traditional

taboos and rituals. Ikeora (2016) says that followers of traditional religions take oaths as a controlling or regulating mechanism. This can, therefore, mean that the oaths taken by my grandparents were among the reasons that they refrained from foregoing their traditional beliefs, because to them breaking the vows meant being punished and cursed and experiencing misfortunes. Beliefs around being punished and cursed can create fear that some Africans like my grandparents had decided not to give up traditional beliefs and participating in traditional rituals.

PEW Research Center (2010), which is an American organisation that provides social and public opinion information as well as demographic trends shaping the USA and the world at large, reveals that from the 1930s the population of Africans converting to foreign religions began to grow. It is possible that those born after 1930, like my parents, were able to convert to foreign religions because as children they had yet to vow to abide by traditional belief systems and therefore had nothing to fear. Having nothing to fear might have resulted in the drop in followers of African traditional religions in sub-Saharan Africa to 13 per cent in 2010 (Pew Research Center, 2010: i).

Despite the drop in followers of traditional religions and the growth of Christianity from 9 per cent in 1900 to 57 per cent in 2010, and of Islam from 14 per cent in 1900 to 29 per cent in 2010, PEW Research Center (2010) pinpoints that the beliefs and practises of traditional religions were still in existence. PEW Research Center (2010), which conducted a study of 25,000 people in nineteen sub-Saharan African countries, including Tanzania, reveals that one in five people in the study say that they believed in the existence of evil spirits, curses and spells. Up to 30 per cent of those interviewed said they kept amulets and traditional sacred objects or charms for good luck, and 20 per cent said they participated in rituals or visited traditional healers to get rid of evil spirits or harmful supernatural powers. Such belief systems have far-reaching effects on sub-Saharan African's economic and social life as they can limit people's reasoning and thus weaken the strategies meant to tackle complex issues such as poverty and other existential challenges, particularly in rural areas where there are limited technological facilities and medical services as well as a low literacy rate.

Beliefs in evil spirits and curses as well as the possession of amulets, charms and sacred objects are beliefs in supernatural powers. Scholars such as Rigaud (2001) and Mesaki

(2009) call such beliefs ‘voodoo’ or ‘witchcraft’ respectively. In my opinion the difference between witchcraft and voodoo is basically in the nomenclature. The name ‘voodoo’ is commonly used in West African countries to refer to beliefs or practises of supernatural power (Desmangles, 1992; Rigaud, 2001; Ikeora, 2016) while the term mostly used in East African countries, including Tanzania, is ‘witchcraft’ (Mesaki, 2009; Mulemi, 2014). Thus, voodoo is a West African phenomenon and witchcraft an East African one. Given my research country context, in this thesis I use the term ‘witchcraft’ to explain the linkage between religion, superstition, fear and hatred and how these relate to the lives of people with albinism.

Tebbe defines ‘witchcraft as ‘secret practices which use supernatural powers to harm others or help oneself at the expense of other people’ (2007: 190). Such a definition means that attacks against people with albinism have connections to witchcraft, as the attacks are conducted with an intentional belief of either harming people with albinism or benefiting from such attacks. In other words, the killers of people with albinism intend to harm, as well as to acquire benefit at the expense of those with the condition. For example, according to Ntinda (2009) the killers of people with albinism use their eyes as a remedy to prevent cheating in sexual relationships, legs as aphrodisiacs and blood, hair, nails, sexual parts and breasts as a source of wealth and prosperity (also see section 4.3).

Witchcraft in Africa, particularly Tanzania, is widespread and continues to be part of an acceptable reality. When, for example, the data of the nineteen sub-Saharan African countries were combined into a single scale to provide an overall picture of where beliefs in the existence of witchcraft were highest, the data of PEW Research Center showed that Tanzania ranked the highest, with 62 per cent of the population showing belief in witchcraft practices (2010: 34). Mbiti (1989, 1999) talks about how religious beliefs can be powerful forces which manipulate people’s thoughts, behaviours and actions. In this case, the high rate of belief in witchcraft in contemporary Tanzania demonstrates such forces. This is especially so when we consider that witchcraft is a secretive practice, is often perceived negatively in media coverage and has no written manuscripts for referencing and nevertheless continues to have followers in the world of science and technology. Literature (Desmangles, 1992; Rigaud, 2001) shows that to date witchcraft beliefs still exist even in some parts of the USA and Haiti. Although, Desmangles (1992) and Rigaud (2001) relate the presence of witchcraft belief systems in the USA and Haiti

to African descendants who were taken to the continent during the 17th century by the slave trade, it is astonishing that such belief systems exist in a country in which there is high scientific and technological advancement.

Mbiti (1989) believes that these persisting beliefs in witchcraft are often transmitted through myths, songs or story-telling from one generation to another. In Tanzania, for example, we often hear stories from or conversations among family members, and Tanzanians of various age groups, gender, education levels, and economic status who have explained albinism and events such as broken relationships, illnesses, misfortunes, accidents and even deaths in terms of witchcraft. Bourdieu (1977) says that habits are a product of history and are often transmitted within a home. Thus, the witchcraft worldview particularly in African countries including Tanzania has been transmitted through homes and has now formed part of some Africans' culture and belief system. For example, a study of the worldview of medical students in a Ghanaian university revealed that forty-one of forty-five medical students surveyed believed that witchcraft was responsible for existential challenges, including medical issues such as diseases and illnesses (Ohene, 2012). In my view, such findings do not only show the alarming beliefs of witchcraft, but also act as a sound warning to African nations about the negative consequences of such beliefs. These negative consequences will be realised when some medical doctors believe that patients suffering from malaria, tuberculosis or cancer have been bewitched. Other consequences will also be realised when some policy-makers and teachers, including those in HE, believe that the poor performance of students, including those with albinism, is because of witchcraft rather than lack of support or teaching and learning facilities. The worst consequences are beliefs currently held by some Tanzanians that body parts of people with albinism are a source of wealth and good luck.

Beliefs in witchcraft often trigger superstition beliefs. Mulemi (2004) in his article 'Superstitions' defines superstitions as beliefs that do not have an empirical basis, or things or phenomena which, although owing their origin to natural and logical causes, are attributed to supernatural power, and which are distorted by fictional imagination. Beliefs surrounding albinism, going by Mulemi's (2004) definition, are superstitions as they have no empirical foundation and, as mentioned above, are connected to witchcraft, that is, supernatural powers. Among superstitious beliefs relating to people with albinism as elaborated elsewhere are those which claim that people with albinism are a bad omen,

that they can cause disasters or contagious diseases, and that they are a result of mothers' adulterous relations. Such beliefs are likely to activate fear and hatred as human beings often fear and dislike bad omens, disasters and being unwell. Likewise, some women would also fear or hate being seen as promiscuous thus feeling hurting to have children with albinism. These superstitions can circulate fear and hatred as they make people to believe that people with albinism bring curses or are a bad omen to societies thus, justifying the harmful witchcraft practices against people with albinism.

Given that witchcraft can active superstitious beliefs which result in the mistreatment of people with albinism, if Tanzania is to eradicate such mistreatment it needs to have strategies which can eradicate the witchcraft beliefs in Tanzanians' worldview. Africans, including Tanzanians, have oral cultures in which stories are told, listened to and memorised (Mbiti, 1989). Such cultures tend to undermine critical thinking and the questioning of unfounded beliefs, practices and stories. This means that critical thinking programmes, such as debates and analytical discussions in schools and universities, would be a good strategy which would help to eradicate witchcraft beliefs. Debates and discussions would enhance students' questioning techniques and critical thinking ability. Another strategy would be to introduce anti-witchcraft programmes in school curricula so as to reorient young peoples' minds from witchcraft beliefs to topics around science and technology. Having reflected upon witchcraft, which is one of the components embedded in African traditional religions, and how it sometimes influences superstitious beliefs and consequently spreads fear and hate crimes against albinism, I now turn to the country context of my study.

1.7 The Tanzanian context

Tanzania is one of the countries in SSA. It is geographically located in East Africa and shares its borders with Burundi, the Democratic Republic of Congo, Kenya, Malawi, Mozambique, Rwanda, Uganda, and Zambia. Given that it shares borders with eight African countries, it is very possible that Tanzania exerts social, economic, cultural and political influence on its neighbours. What happens in Tanzania, such as the killings and the amputation of body parts of people with albinism, can easily spread to other countries as indicated in Chapter Four because there is close and frequent interaction and migration among people and tribes residing on the Tanzanian borders. For example, the *Maasai*

people in Tanzania and Kenya all speak the same language, and have similar traditions and culture. They also have free border interactions, as do the *Luo* people in Kenya and Tanzania and the *Haya* and *Toro*, *Nyankore* and *Bakiga* in Uganda, to mention a few.

According to the 2012 national census, Tanzania had a population of approximately 44.9 million people. The current population, however, is estimated at 49.5 million people (World Population Review, 2014). Given its tropical climate, the majority of Tanzanians are dark in colour. It is estimated that only one per cent of the population is non-black African (World Population Review, 2014), and consists of Tanzanians whose ancestors emigrated from Asian, Middle Eastern or European countries. The small number of non-black Africans in Tanzania means that black Africans dominate the country. Thus any person who differs from this norm like people with albinism, therefore, is likely to stand out as an outsider who does not belong (Ahmed, 2012; 2000).

Tanzania is a union of two countries, Tanganyika and Zanzibar. Tanganyika received its independence from the British government on 9 December 1961 and a year later became a republic. Zanzibar received a provision for full self-government from the British government on 10 December 1963. A month later, on 12 January 1964, a revolution took place and the Peoples' Republic of Zanzibar was established. A few months later, on 26 April 1964, a union between Tanganyika and Zanzibar was formed and Tanzania was born.

The Union of Tanganyika and Zanzibar was followed by the Arusha Declaration in 1967. The declaration formulated the *Ujamaa* ideology. *Ujamaa* is a Kiswahili word meaning 'family-hood'. The *Ujamaa* ideology, which has come to mean African Socialism, emphasised human dignity, equality of opportunities, and the equal distribution of society's resources (also see Section 1.6). It also emphasised the importance of non-exploitation, social integration and the inclusion of all groups of people in the society (Nyerere, 1968). In its totality, the ideology propagated the idea of collective development and emphasised that every Tanzanian citizen was *ndugu*, meaning a sibling to each other, which meant loving each other. This therefore required every citizen to have an equal stake in society (Nyerere, 1968), which could mean what Ahmed (2010) terms a promise of happiness.

In her notion of a promise of happiness, Ahmed (2010) analyses the link between happiness and the promise of a good life. Here, she argues that certain ideas and objects are often

perceived as happy ideas or objects, which can promise such a life, and lists those ideas and objects as marriage, family and heterosexual intimacy. In the context of Tanzania, I can say that the ideology of *Ujamaa* can be perceived as the promise of a good life. Although the level of happiness among Tanzanians was unknown during the *Ujamaa* era, it has been low during the Structural Adjustment Policies (SAPs). A study by the team of experts, Helliwell et al. (2015), which measured the level of happiness and well-being of people in 158 countries worldwide, places Tanzania at number 146, indicating that the country has many unhappy people.

Working towards the establishment of the *Ujamaa* ideology in his book *Ujamaa: The Basis of African Socialism*, Nyerere, (1962) gave an example of true African Socialists as people who do not love one class of people and hate the other. He went on to emphasise that a true African Socialist:

(d)oes not form an alliance with the brethren (sic) for the extermination of the non-brethren (sic). He (sic) rather regards all men (sic) as his brethren - as members of his ever-extending family (Nyerere, 1962: 5).

Nyerere's (1962) views can be interpreted and critiqued as not gender sensitive for the use of male words such as 'brethren' or 'men'. He could have used such words because in the 1960s, when he made the statement, patriarchal words such as *mankind* were still largely used to mean humanity because 'humanity was male' (de Beauvoir, 2011[1949]: 5). As a feminist researcher, I do not support such words or views, but the point of my interest was his advocacy for a society that values and respects all human beings irrespective of their gender, class, race or physical or mental ability differences and even their albinism, when he said that:

(o)ur recognition of the family to which we all belong must be extended yet further - beyond the tribe, the community, the nation, or even the continent- to embrace the whole society of [humankind]. (Nyerere, 1962: 5).

These values and principles led to Tanzanian politics and people making the country one of the most peaceful countries in Africa until 1991, when the Zanzibar Declaration was enacted. Although the Zanzibar Declaration did not specifically mention the abandonment of *Ujamaa* values and principles of collective development, it ushered in the creation of new neoliberal ideologies by adopting SAPs which were stipulated by the International Monetary Fund (IMF) and the World Bank.

SAPs demanded, among other things, the liberalisation of trade, cost sharing, retrenchment of workers in the public sector and the promotion of privatisation (Wagao, 1990; Ponte, 1998 cited by Varvus, 2005: 180). The adoption of such policies meant a shift away from state control and towards privately-owned means of production. In other words, it meant a shift from collective ownership to individual ownership or away from African values (see section 1.6). The government was no longer responsible for the welfare services of its citizens, whereas under *ujamaa* policies, public services had been free, including education from primary to HE.

When government withdrew from such services I would say its promise of happiness for its citizens was abandoned. With cost sharing, people – the majority of whom are poor (see World Bank, 2015a) - were now required to contribute towards public services such as education and thus the predominantly free public services earlier enjoyed by all citizens was abandoned. Services like education were privatised. Private schools, which had better learning and teaching facilities and a better environment, were established and promoted in place of a unified public school system (Mbilinyi, 2003).

Private schools are mostly accessible to a few affluent and elite groups in the country (see the percentages of middle and high classes in Section 1.2). The public schools, accessible by the majority of Tanzanians from less affluent families including most disabled students, had limited teaching and learning facilities and non-conducive learning environments (Komba and Nkumbi, 2008). Class differences therefore began to appear in the education system as those from schools with better facilities excelled and had better opportunities to interact and occupy HE spaces. Those from public schools, on the other hand, became victims of blame for their own misfortune, or for failing to help themselves, as propagated by neo-liberal ideology (Mbilinyi, 2003).

As mentioned above neo-liberal policies also demanded government retrenchment. This meant that a number of people went out of formal employment and were thus involved in informal employment for survival, which widely made peoples' economic situations worse off. For example, a study by Osberg and Bandara (2012), which looked at the economic situation of 4,986 people in various regions of Tanzania revealed that 99 per cent of the participants indicated that their economic situation in 2007 was worse than that in 2004, showing that more people were being continuously pushed into poverty;

now 65 per cent of the Tanzanian population is categorised as living in poverty (World Bank, 2015a). The World Bank Report (2015a) further reveals that 28.2 per cent of the Tanzanian population lives below the poverty line where they cannot meet their daily basic needs, including their food supply. The Bank's report estimates that the national basic needs poverty line was Tshs 36,482/- (UK £12) per adult per month whereas the national food poverty line per adult per month was Tshs 26,085/- (UK £9), which was below the World Bank universal extreme poverty line of less than US \$1.25 per person a day (World Bank, 2015b).

This kind of poverty means the majority of Tanzanians are desperate merely to survive. Ahmed (2010) tells us that when people are desperate to survive they can seek out their own ways of achieving a good life or their own means of finding happiness. Under current neo-liberal policies, which stress privatisation and free market development, people in Tanzania depend on savings, inheritance, loans or investments in their search for a good life. But those who might not qualify for these resources may, in their desperation to survive, seek out illegitimate ways of achieving happiness or a good life, such as corruption or burglary. In some cases, the search for a good life can be influenced by myths or beliefs. For example, in a country like Tanzania where 62 per cent of people believe that charms and witchdoctors can prevent or offset bad omens, suffering or hardships (PEW Research Center, 2010), it is possible that some would believe – and even act on the belief - that the body parts of people with albinism are a means of achieving wealth, which is often associated with happiness. Such beliefs might have occurred after people had despaired of succeeding in life without the support of an extra ordinary power. Having looked at the country context of this research, it is equally important to discuss the education system.

1.8 The Tanzanian education system

The education system in Tanzania, according to Omari (1982), is a mixture of the German and British education systems. Our system consists of five levels of education: pre-primary education, primary, ordinary secondary education ('O' level), advanced secondary level ('A' level) and HE. The pre-primary is often for two years followed by seven years of primary education, at the end of which seventh-year students sit a national examination to qualify for secondary education. Secondary education consists of two levels. The first level is the ordinary level, which takes four years. At the end of the fourth

year, candidates sit a national examination and upon successful completion are awarded Ordinary Certificate of Secondary School Education (CSSE), then progress to advanced level secondary school education. The second level is the Advanced Secondary School Education (ACSSE), which lasts two years. Upon successful completion of this level candidates are awarded Certificates of Advanced Secondary School Education (ACSSE) and can progress to HE.

A renowned Tanzanian scholar, Mkude (2011), points out how these pathways are blind to the life or educational experiences of those aspiring to enter HE as they often subject each candidate to equally stiff competition. Mkude (2011) indicates that those from public schools are subjected to competition with those from private schools who have better learning and teaching environments and are from affluent families. Adding to Mkude's (2011) argument, I would say that students with disabilities, such as those with albinism, are also subjected to the same scrutiny as those without any disabilities, which limits their chances to participate in HE. Reay (2012) suggests that in order for an education system to be considered good, it should allow just competition.

A study by Haki Elimu (2008) revealed that some schools in Tanzania lacked essential teaching and learning facilities, and the materials necessary to facilitate the learning of disabled students. The study also revealed that some primary and secondary teachers also lacked the skills and training necessary to teach disabled students. This lack of training, according to Haki Elimu (2008), caused some teachers to refuse to have students with special needs in their classes. Lack of supportive devices and skilled teachers affects the learning processes of disabled students; subjecting them to the same examinations as those without disability therefore constitutes an unjust competition whereby disabled students will always be denied opportunities to participate in education, including HE.

HE in Tanzania, as compared to countries in the Global North, is a recent phenomenon. It started 54 years ago when the now University of Dar es Salaam (UDSM), which is the oldest university in Tanzania, was established as a college of the University of London in 1961. The expansion of HE in Tanzania has been slow compared to other countries in SSA (Cooksey et al., 2003). The HE system in Tanzania falls into two categories: university and non-university (TCU Guidebook, 2014). According to this classification, non-universities are institutions that offer three-year courses, mainly technical bachelor

degrees, whereas universities are those institutions that offer the standard bachelor degrees and postgraduate degrees (TCU, 2014).

Following the adoption of neo-liberal policies as mentioned above, drastic HE expansion in Tanzania began in 1995 when the HE sub-sector was liberalised and private institutions were allowed to operate. Basing on HE classification, there are now 75 HE institutions, of which 52 are universities and 23 are non-university-level institutions. My research focuses on the experiences of students with albinism in universities in Tanzania, of which 40 are privately-owned and 12 are publicly-owned. My focus is on both public and private universities in Tanzania. Out of the 75 HE institutions, only three have supportive devices and services to accommodate students with various disabilities.

Exploring the locations within HE of students with albinism was challenging because of limited data. However, the data that I collected revealed that there were 20 students with albinism who were located in 12 universities where they were undertaking different degree programmes. Of these 20, eight were female students and 12 were male, which corroborates the existing literature suggesting that disabled students who participate in HE are often male (Barnes, 2007; Mumba, 2009). I also found that eight students with albinism were located in public universities and 12 students with albinism were in private universities. This indicates that students with albinism were widely located in private universities, although some public universities, as single entities, enrolled more students with albinism than single private universities: some private universities had only one student with such condition whereas in one public university there were four students with the condition, following various degree programmes. Here we need to bear in mind that the 20 students with albinism include the seven students with albinism participants who were currently undertaking studies in HE but not the seven graduates with albinism in this study who had already completed their studies.

In terms of programmes, I found that while no students with albinism were studying agriculture, natural sciences and STEM, two of them were undertaking BMA programmes, six were pursuing education arts programmes and one student was enrolled on an education science programme. I also found that there were 10 students located in the law and social science cluster and just one in subject areas allied to medical sciences. These findings

suggest that students with albinism in Tanzania are mostly located in the subject areas of law and social sciences.

In Tanzania, data reveal that most disabled people reside in rural areas (NDS, 2008). However, my research reveals that students with albinism were mainly located in universities in urban areas; indeed, of the 20 students with albinism only two were enrolled in a university located in a rural area. The low number of such students in rural universities may be because Tanzanian universities, although located in different regions of the country, are mostly located in urban areas.

Returning to my earlier discussion of neo-liberal policies in relation to HE, the implementation of SAPs in Tanzania demanded cost-sharing in various areas of public services, including the provision of HE. This means that HE in Tanzania is not free. Therefore, students entering either public or private institutions are required to pay a tuition fee. However, in terms of financial opportunities there are students' financing arrangements under which eligible students receive either loans or grants to pursue HE studies (Ministry of Education and Vocational Training (MOEVT), 2014). Students' Loans, according to the Tanzania Higher Education Students' Loan Board (HESLB) Act, (2004), are given specifically to 'needy' students. The HESLB defines a 'needy' student as one whose parents are economically disadvantaged. There is no doubt that student loans have contributed to a large extent to the ease of entry, retention or completion of the students and graduates who were interviewed in this thesis, particularly the 11 participants with albinism from less affluent families. But the Tanzanian Education Sector Analysis conducted by United Nation Education and Scientific Organisation (UNESCO) (2011) revealed that only 10 per cent of students in HE benefiting from such loans were from less affluent families. This could mean that there were other students with albinism from less affluent families who could not access the loans and therefore could not either participate in or continue with HE. In the 2014/2015 academic year, a total of 59,887 students were selected to enter 52 universities and out of these 1,766 students could not continue with their studies for financial reasons (TCU, 2015). This is an indication that a lack of financial support can affect the retention of HE students including students with albinism.

For further financial opportunities, students are also financed through student grants. Student grants are specifically issued to students pursuing the Doctor of Medicine degree

programmes (MOEVT, 2011) and issued to medical students irrespective of their social-economic status. Evidence indicated that in Tanzania the majority of students entering science-related programmes, including medicine, are often from privileged backgrounds (Cooksey et al., 2003; Morley et al., 2010). Given the level of poverty that often surrounds disabled people in Tanzania as indicated above, it is obvious that few disabled students, including those with albinism, interact with student grant opportunities.

My data, for example, reveal that it was not until 1989, 28 years after the establishment of university education in Tanzania, that the first student with albinism (male students) entered HE. This means that for 28 years after Tanzania's independence in 1961, the country's HE system had been excluding people with albinism, contrary to the country's constitution. Articles 9 and 11 of the Constitution of Tanzania declare the right of every citizen to pursue education in their field of choice up to the highest level, in accordance with their merits and abilities (URT, 1978). As mentioned above, some disabled people have limited rights.

In terms of admission, more opportunities are made available through the Open University of Tanzania (OUT). OUT, as indicated by its name, has an open and distance mode of delivery. It has centres across the country and charges a minimal tuition fee of Tshs 360,000/- per annum (approximately £120) (TCU Guidebook, 2014). The increase of opportunities has gone hand in hand with the increase of students that is from 40,000 students in 2005 to approximately 200,981 students in 2015 (TCU, 2015). Although statistical data on the numbers of disabled students in HE is limited, as already mentioned literature indicates that the beneficiaries of HE opportunities are often from affluent families (Cooksey et al., 2003; Morley et al., 2010). This could therefore mean that students with albinism from less affluent families are unlikely to fully benefit from the increased opportunities, illustrating that widening participation strategies in HE can sometimes ignore disabled students (Morley et al., 2010).

To participate in HE in Tanzania, a candidate must meet the prescribed entry requirements. According to TCU (2014) one of the bodies which regulates and sets entry criteria into university level institutions in Tanzania, candidates can enter through four pathways: direct entry, equivalent qualifications, re-sitting and recognition of prior learning. The direct entry pathway is based on 'A' level examination performance; the equivalent

qualifications pathway considers a diploma or foundation certificate. The re-sit is for those who do not meet the required HE admission criteria in their first examination sitting (National Examination Council of Tanzania (NECTA), 2014). These candidates can re-sit their 'O' or 'A'-levels national examinations.

In recent years Tanzania has introduced a new criterion which widens access to HE. This new criterion, known as Recognition of Prior Learning (RPL) Examinations, caters for candidates who completed primary education but were not selected for secondary education. These candidates, however, must have undertaken some extramural or professional development courses and had relevant work experience in the field for which they apply. Nevertheless, only five out of the 52 universities have adopted RPL and only into specific programmes.

The three non-traditional pathways, the RPL, the re-sit system, and equivalent qualifications have provided opportunities to students who might not have had the opportunity to participate in HE including those living with albinism. For example, primary school leavers with professional certificates, and those who did not complete high school have now been given an opportunity to interact with HE and become students in various HE institutions in Tanzania.

Given the challenges and limited chances that students with albinism encounter in their interplay with HE opportunities, it was surprising, firstly, how the 20 students with the condition whereby eight were female students, that were seen to be studying in HE institutions, negotiated the stiff competition and succeeded in being among the 200,981 students enrolled in HE in Tanzania (TCU, 2015); and, secondly, how they competed against Tanzania's 2.5 million HE population cohort (UNESCO, 2011) and won the competitive game. The few and brave, whom I believe have displayed extraordinary agency in negotiating their access into HE, need to be nurtured and protected by removing barriers within or outside the HE settings that threaten their success. Studies in Tanzania on disability in HE (Tuomi et al., 2014; Morley and Croft, 2011; Mwaipopo et al., 2011; Morley et al., 2010) informed us that the barriers within the HE settings were access to built environments, and teaching and learning resources as well as attitudes, ignorance and prejudice. This study adds to their work by illustrating that emotions, symbolic violence and misogyny can constrain and impede the participation of disabled students, including

students with albinism, in HE, but because of various enablers they succeed to enter HE. I now provide the structure of my thesis.

1.9 Thesis Structure

Chapter Two presents a review of relevant literature in the field of disability in HE. This focuses on SSA, particularly Tanzania, but also refers extensively to literature from Britain, which shares with Tanzania historical linkage and similarities in the education systems. Chapter Three focuses on the ‘how’ of my research, in which I reflect upon the epistemological and methodological approaches which were adopted in the study. I also discuss the research strategies by describing the research process, design and ethical issues that emerged during the course of the research process and conclude with an account of how I analysed my data.

Chapters Four, Five and Six present the findings of this study and emphasise the experiences and voices of students with albinism, giving reference to gender issues through the voices of women with albinism participants. Each of the three chapters discusses separately a theme that emerged in the data analysis in relation to the educational and general life experiences of students with albinism. The theme in Chapter Four is emotions, in Chapter Five, misogyny and in chapter six, structure and agency. Chapter Four draws upon Ahmed’s (2000; 2004; 2012) notion of affective economies and fear of difference and Pierre Bourdieu’s (1984) notion of symbolic violence to analyse and explain emotions in discussing Ahmed and Bourdieu’s notions. Here I discuss and present their theoretical framework. Chapter Five draws upon Simone de Beauvoir (2011 [1949]) and other feminist theorists such as Greer (1970), Morley (1992) and Rich (1976) to analyse and explain misogyny in the lives of students with albinism. A feminist theoretical framework is also discussed and explained in this chapter. Chapter Six adopts Archer’s (2000) notion of internal conversation and reflexivity to analyse and explain structures and agency in the life experiences of the people with albinism who took part in my research and discusses Archer’s theoretical framework. Here I look at the internal conversation and reflexivity of the 14 students with albinism in this research and how it enabled their participation in HE. Chapter Seven is the conclusion, in which I discuss my research findings and attempt to answer my research questions in relation to them. From such discussions, I reflect on the contribution of this study to the body of knowledge relating to albinism and HE. This

chapter also indicates research implications at both institutional and national level and provides recommendations and reflections on future research possibilities.

1.10 Research Limitations

This study is a case study research. My case is albinism. Case studies have been criticised for diverse reasons (Campbell and Stanley, 1966; Dogan and Pelassy, 1990; Diamond, 1996, all cited by Flyvbjerg 2006: 3). Some of these criticisms are that the findings of case studies are not generalisable to the entire population, which would mean that the experiences of the 14 students with albinism studied here cannot be indicative of the experiences of students with the condition beyond the four institutions that were the site of this research, or even beyond the Tanzanian context. However, Flyvbjerg (2006) argues that in social science, the strategic choice of case can widely add to the generalisability of a case study and gives as an example a case study of a successful industrial centre going by the name of Luton. According to Flyvbjerg (2006), Luton had companies known for their high wages, social stability and middle-class identities; however, the study discovered that even at Luton a working-class culture prevailed, allowing a generalisation of the persistence of class identity.

Denzin and Lincoln (1994) and Yin (1994) suggest that we can use multiple data collection strategies or different data sources to generalise our findings. Given this, I believe it is possible to generalise from my own findings because, as mentioned above, I have used multiple data collection methods and different data sources. In addition, I have used various theories to explain the experiences of the students with albinism who participated in my study. Moreover, my aim is ‘not to prove anything, but rather to learn something’ (Eysenck, 1976: 9) about the experiences of students with albinism in HE. For all these reasons, my findings are generalisable, and my intention is to allow readers to determine the transferability of my study to other contexts (Lincoln and Guba, 1985). I now turn, therefore, to the existing literature on disability in HE to explore what is known about those with albinism in HE.

Chapter Two

Disability in Higher Education: What Do We Know About It?

2.1 Introduction

This Chapter critically examines the literature on disability in HE. Specifically, the chapter looks at the literature that focuses on the experiences of disabled students in HE in terms of constraints and support. Such literature shows that in SSA, including Tanzania, studies focusing on disabled students are scarce and limited (Mumba, 2009; Chaitaka, 2010; Morley and Croft, 2011; Mwaipopo et al., 2011). Given that the literature in the country and regional context of this thesis was limited, I drew extensively upon the literature deriving from the project WPHEGT (Morley et al., 2010; Morley and Croft, 2011; Mwaipopo et al., 2011) and from a recent study on the experiences of disabled women at the University of Dar es Salaam (Tuomi, et al., 2015). In terms of the regional context of my research, I drew upon the literature from SSA, specifically Kenya, Zambia and Zimbabwe (Mumba, 2009; Chataika, 2010; Opini, 2012).

Globally, I drew particularly upon literature on disability from the UK (Tinklin and Hall, 1998, 2006; Barnes, 2007; Riddell et al., 2006; Fuller et al., 2004, 2010). I chose to focus on UK literature because, on the one hand, there is rich literature on disability in HE; and, on the other, because the UK has historical links with Tanzania. As I said in the introduction, Tanzania was a British colony and the education systems of the two countries share some similarities; for example, both countries have 13 years of formal education including ordinary and advanced level secondary school education. Moreover, as already mentioned the first university in Tanzania, the University of Dar es Salaam, was established as a college of the University of London before acquiring its fully-fledged university status approximately 55 years ago. This shows the close similarities between university systems in Tanzania and the UK.

Given that models of disability can provide a good understanding in the exploration of the experiences of disabled students in HE (Mwaipopo et al., 2011), this chapter also engages with literature on different models of disability. The literature on such models are mainly from the Global North. The five models of disability that I looked at thus provided me

with a good understanding of disabling factors that influenced the life experiences of the 14 students with albinism who took part in this research. Moreover looking at different models enabled me to understand the type of model that universities in Tanzania widely practice.

As I have said above, this chapter focuses on existing literature on the barriers and support that disabled students encounter in HE. To me, such a focus means exploring the literature on widening HE participation. Tanzania has policy goals on widening participation in HE. However, according to Morley et al., (2010) such goals have often focused on gender and paid less attention to other non-traditional HE students, such as disabled students. As a result, little is known about disabled students, particularly those with albinism in terms of data and their experiences. Morrice (2013a), a British scholar, in her research on refugee students in UK universities found that there was very little knowledge of their university experiences because they were often not tracked and were thus subjected to the same challenges as non-refugee students. This observation can also be made of the experiences of disabled students, particularly students with albinism: as they are not tracked, little is known about them and consequently they are subjected to the same treatment as those without albinism. Chaitaka et al., confirm the limited attention often accorded to disabled students in SSA, informing us that ‘in some SSA countries, including Tanzania, when education for all is discussed issues of disabled students tend to be given a low profile’ (2012: 388). Likewise, Graham, (2014) suggests that children with disability were highly excluded from education because of their invisibility in national data including those on education. Before focusing on the literature on disability in HE, I briefly review the literature on HE in general.

2.2 A look on HE participation globally

Literature on HE participation in many countries shows that the sector is no longer considered as a luxury item, but as a necessity as it is conducive to both individual and national technological, economic and social development (Meyer et al., 2013). Most countries have therefore now attempted to widen their HE participation rates. In this context the British Council (2012) report predicted that between 2011 and 2020 there would be a global growth of 21 million HE students or an average 1.4 per cent global increase of HE students every year. At the global level, there has already been an increase

in the gross enrolment rate (GER) of the HE cohort age from 18 per cent in 1999 to 27 per cent in 2009 (UNESCO Institute of Statistics, 2011). Even the SSA region, which often lags behind in HE enrolment, has had an encouraging increase to 6.3 per cent in 2009 from 3.9 per cent in 1999 (UNESCO, 2011). Similarly, Tanzania has also had an increase in the HE GER from 1.4 per cent in 2005 (Mwaipopo et al., 2011) to 2.5 per cent in 2009 (UNESCO, 2011).

These globally improved HE participation rates have had a massive impact, even on some non-traditional HE students, particularly women. The global female HE GER is now higher than that of their male counterparts (UNESCO, 2011). Although these positive developments in women's participation have taken place in countries of the Global North there has also been noticeable improvement in women's HE participation in the Global South. In Tanzania, for example, the annual admission rate of women has also improved to reach 36.2 per cent in 2012, up from 25 per cent in 2002 (TCU, 2013). Despite the commendable improvement in women's participation in HE globally, Morley (2011) in her article *Misogyny Posing as Measurement Disrupting the Feminisation Crisis Discourse*, informs us that HE is still male-oriented in terms of its values, norms and processes. For this reason, even though women are participating in HE they are still outsiders because its values, norms and processes are not in their favour.

The spirit of HE participation improvement has spread to disabled students as well. Global North literature such as that of the UK continuously indicates that more disabled students are now entering HE education, which is an indication of the positive impact of widening participation policies and strategies. Morley and Croft, however, remind us that 'global massification of HE can hide unequal participation rates' (Morley and Croft, 2011: 383). This hidden inequality also exists in disabled students entering HE. Colin Barnes (2007), for example, notes that most disabled students participating in HE in the UK are from upper or middle class backgrounds, male and not from a minority ethnic group. Riddell et al. (2005) made the same observation in their UK research project investigating the impact of multiple policies on the participation and experiences of disabled students in HE in Scotland and England. UNESCO (1995) cited by Barnes and Mercer (2003) informs us that in the Global South, females with disabilities often have limited access to education, including HE. Supporting UNESCO's (1995) observation, Mumba (2009) in her study on students with disability in Zambian HE also observed that in Zambian universities the

majority of students with disabilities were male. Nevertheless, Mumba (2009) quoted data from UNESCO (1997), which showed that at the University of Botswana more students with disability studying in HE were female.

In Tanzania, few social indicators are monitored on application (Morley et al., 2010). There is therefore limited statistical data on disabled male and female students in HE. This could be an indication that Tanzania pays less attention to issues of access and participation where disabled students are concerned. However, Possi (1996), a Tanzanian female scholar, conducted a study approximately two decades ago on the gender and education of people with disabilities which found that few disabled women enter HE, compared to the number of disabled men. Despite the limited data in the Tanzanian context on disability in HE, what is apparent is that the participation rate of disabled students has remained low and, in some cases, absent (Morley and Croft, 2011; Mwaipopo, 2011). Likewise, disability has remained one of the key exclusionary factors for educational participation in Tanzania, as well as in other African countries (World Vision, 2007). In Tanzania, for example, of the 55,314 students enrolled in HE institutions in the 2005/6 academic year, only 54 students were disabled (Mwaipopo et al., 2011).

Ebersold (2008), in his work on adapting HE to the needs of disabled students in Canada, France, Germany, Switzerland and the UK, relates such low participation rates to the weaknesses of education systems. He suggests that the system failed to respond adequately to the academic capabilities of disabled students. Likewise, Jackson (2000), in his work on learners who are more likely to be excluded from educational participation, suggests that the low participation of such learners is not because of their characters or lack of capabilities but because of the weaknesses that exist in the education system, which fails to capture their specific individual learning needs. Tinklin and Hall (2006) share the same views and pinpoint the weaknesses of university systems in Scotland, where universities continue to provide support to disabled students instead of removing the constraints. Morley and Croft (2011), when looking at agency and advocacy in HE disabled students in Ghana and Tanzania, pinpointed existing factors that affected the smooth functioning of some universities in those countries. Among other things, they pointed to inadequate teaching and learning facilities as well as the learning environment, which can affect the academic capabilities of students including those with disabilities, meaning that some students may experience HE in a particular way.

Studies conducted in South Africa, Zambia and Zimbabwe (Matshedisho, 2007; Mumba, 2009; Chataika, 2010) show that disabled students in HE often drop out or experience low achievement because universities often provide them with limited academic and non-academic support. These literatures, which derive from SSA studies, also reveal that universities in this part of the world usually provide limited support because they rarely have plans to change their university environment to cater for students' special needs. They see these universities as lacking planning strategies in areas of physical structure and/or curricula which are accessible to all students (Matshedisho, 2007; Mumba, 2009; Chataika, 2010). This could mean that universities in SSA countries, including those in Tanzania, consider disability to be an individual problem which needs a cure, and therefore focus their strategies in line with the medical model of disability. Before proceeding to examine the literature on the experiences of disabled students in HE, I find it important, as I have said above, to first look at models of disability.

2.3 Disability Models

In Tanzania, according to Morley et al. (2010), disability is often viewed and discussed within the two traditional models, namely the medical and the social model. However, Shakespeare (2014) mentions at least five models of disability, listing them as the medical, social, social-relational, cultural and interaction models. The medical and social models are widely debated (Morris, 1991; Crow, 1992; French, 1993; Thomas, 2004, 2007; Barnes, 2007; Oliver, 2009; Shakespeare, 2006, 2013, 2014). The medical model relates disability to an individual's impairment thus placing emphasis on individual inabilities, welfare and medical support. This model tends to see the challenges often experienced by disabled people as a tragedy that derives from the person's impairment. Critiques of this model suggest a social model (Oliver, 1983, 1990, 1996, 2009; Hahn, 1986; Barnes, 1996). They see the medical model as widely creating a negative view of disability and strengthening dependency as they suggest that it focuses more on bodily deviance, disorder and deficiency, reducing disability to an outcome of only individual impairment and providing us with only one dimension of analysis. Priestly (1978) sees the unit of analysis in the medical model as beliefs and identity.

The social model places emphasis on societal constraints thus shifting the blame for disability from people with disability to an unfair and oppressive society. In this context,

disability is seen as stemming from social structures that have failed to adjust to the needs and aspirations of individuals (Hahn, 1986). Social structural constraints are thus taken as reasons for the disablement of disabled people. In other words, researchers adopting the social model see disabled people as being disabled by environmental, cultural and economic structures that exist in societies. While scholars like Oliver (2004) see the social model as one which can adequately explain the experiences of disabled people, Shakespeare (2014) argues that it cannot adequately explain the complex interplay of individual and structural factors, given that it focuses more on structures and less on individual impairment. It thus reduces disability to an outcome of only social constraints and provides us with only one dimension of analysis, just like the medical model. For Shakespeare (2014), impairments are also important in analysing disability because these may be permanent, occasional, progressive or fatal. This suggests that only looking at societal or environmental factors may lead me to overlook the low vision impairment which can sometimes affect students with albinism's ability to interact with HE opportunities.

Another model of disability is social-relational, as suggested by Thomas (1999; 2007; 2012). The social-relational model focuses on constraints that affect peoples' doing and being (Thomas, 1999; 2007; 2012). Watson (2012) and Shakespeare (2014) criticise this model for its limitation when addressing issues of peoples' discrimination. They see the model as having limited means of distinguishing between effects that emerge from impairment and those which emerge from structural or cultural constraints. The cultural model is often linked with an American scholar, McRuer (2006), and an Australian scholar, Campbell (2009). It places more emphasis on social discourse and cultural roles in the understanding of disability.

The interaction model was suggested by Shakespeare (2014) and some disability theorists in the Nordic countries. This model integrates the medical and social model, suggesting that disability is an interaction between individual and structural factors (Shakespeare, 2014). This model suggests that both the impairment (internal) and socio-cultural (external) factors of an individual are a cause of disability and neither of them can be reduced. My understanding of this perspective is in line with Archer's (1988, 1995, 2000) notion of structure and agency, which is explained in detail in Chapter Six. Archer (1988; 1995; 2000) uses her theory of morphogenesis to explain the interrelationship of structure and agency. She believes that structure and agency influence each other. In Chapter Six I

explain her theory of morphogenesis to analyse the experiences of the 14 participants with albinism in interacting with HE opportunities. The findings from these analyses indicate an interaction between visual impairment and the structural and cultural conditions in the life experiences of the 14 students with albinism.

In understanding the experiences of the 14 students with the condition, neither their poor vision nor their social, structural and cultural constraints and enablement were reducible, as they all influenced each other. In this context, I drew upon the interaction model of disability to capture both the external and internal conditions, including the cultural factors that surround the life experiences of students with albinism. While Tanzanian policies recognise that social and cultural factors influence how people perceive disability, HE, as mentioned above, often treats disability as an individual issue (Mwaipopo et al., 2011). Disabled students are therefore often not included in the widening of participation strategies or policies. Although in practice disability is treated as an individual issue in Tanzania and some other SSA countries, Chataika (2007) points out that the medical and social models often dominate disability research in this part of the world. However, it has become clear in recent years that the interaction model has been applied to researching disability in SSA. For example, Chataika (2010), a researcher from Zimbabwe, has successfully used Shakespeare's (2006) interaction model to capture the life experiences of disabled students in HE in Zimbabwe. In analysing her data, Chataika (2010) felt it important to investigate the interaction between various personal and structural factors affecting her participants. Having looked at the various models of disability, I now proceed to discuss the barriers that impede the participation of disabled students including students with albinism in HE.

2.4 Barriers impeding HE participation

A vast literature exists on the experiences of disabled students in HE, and it has continuously indicated constraints (Fuller et al., 2004; Chataika, 2010; Morley and Croft, 2011; Gavira and Morina, 2014; Tuomi et al., 2015). Among those often highlighted are learning and teaching constraints, the learning environment and peoples' attitudes. The persistence of constraints imposed on disabled students suggests a need for a HE environment that would allow disabled students to adequately learn, fully participate and have a sense of belonging in HE. The vast literature from both the Global North and

South shows, however, that disabled students in HE are often seen as outsiders or stranger danger (Ahmed, 2012). This is because the curriculum, teaching, learning and assessment are often designed with an assumption of homogeneity (Riddell et al., 2005). Disabled students in HE are often thus faced with challenges.

Fuller et al., (2010) in their UK mixed-method study on the learning, teaching and assessment experiences of disabled students in HE, found that the 173 disabled students who participated in the research experienced teaching and learning as stressful and full of anxiety. This stress and anxiety was brought about by the teaching style that excluded disabled students, as it did not consider the specific individual needs of students. Fuller et al. (2010) identify the teaching styles referred to as talking too fast and removing transparencies before the disabled student had finished copying the notes. Likewise, in a study which focused on disabled students and looked at inclusive policies and practices in social science and law classrooms in HE institutions in Spain, Gavira and Morina observed that the policies and practices there were ‘hindering the learning and limiting membership and active participation on equal terms’ (2014: 367). This reveals that learning and teaching practices in some universities in Spain were not paying attention to students’ special needs, indicating that university systems, including those in Tanzania, can sometimes hinder student learning. Further more a study by Borland and James (1999) on the experiences of disabled students in a UK university found that admission into some programmes particularly science related programmes had some restrictions on the basis of their physical ability.

Morley and Croft (2011), in their work on the experiences of disabled students in Ghana and Tanzania, which derived its data from the WPHEGT project, also found that the teaching style of some teaching staff did not accommodate the specific needs of students. Likewise, in my study I found that there was exclusion of students with albinism in the teaching style of some teaching staff. The teaching staff in general were seen to have assumptions and beliefs that all students could see what was on their power point presentations. This was an indication like in universities in Spain disabled students in Tanzania including students with the condition were learning in a system which functioned without considering their unique characteristics. I would therefore say that students with albinism in Tanzania have been experiencing what the British scholar, Hinton-Smith (2012) found in her study on lone parents. Hinton-Smith’s (2012) research found that lone parents had experienced

unfriendly university arrangements. Similarly, I would say that universities, including those in Tanzania, have been places where student support is not guided by policies or practices but, rather, sometimes depends upon the sympathy of university staff (Fuller et al., 2010).

Non-conducive learning environments have been barriers for most disabled students in their participation in HE. Morley et al, (2010) talk about non-conducive learning environments at universities in their case study and raise the issue of overcrowded and inaccessible classrooms and buildings. Tuomi et al. (2015) raise the same issues at the university, which was their site of research. Such overcrowded classrooms and inaccessible buildings and classrooms can affect participation, particularly that of disabled students, as I note in my research where overcrowded classrooms were seen to negatively affect the fully participation of the 14 students with albinism as well as the good intended support services that were given to students with albinism.

Furthermore, Mkude (2011) in his paper which derives its data from the WPHEGT project, makes the same observation about overcrowded classrooms and inaccessible buildings. However, Mkude (2011), a renowned scholar in university management in Tanzania, argues that some Tanzanian universities would like to have supportive services for disabled students but cannot because of limited government subsidies. He thus blames the government for the lack of such services in universities. While I do agree with Mkude that lack of government financial support can affect the provision of supportive services, I note that some private universities also lack such services. For example, out of the 40 privately-owned universities in Tanzania, only one has such facilities. In terms of public universities, only two provide such service. I am therefore led to believe that HE institutions see disabled students as ‘not ideal HE students to deserve any investment’ (Morley, 2011c: 229).

Riddell et al. (2005) do not differ much from Mkude’s (2011) view. Riddell et al. (2005) feel that disabled students can sometimes pose financial challenges to universities as their access does not only require the improvement of infrastructure but also review of curriculum, teaching and learning as well as assessment systems. The arguments of both Mkude (2011) and Riddell et al. (2005) refer to the limited financial ability that was often availed to universities. This does not differ from the findings of Tuomi et al.

(2014), which reveal that most of the assistive devices available in some universities in Tanzania were not up to date, while others needed replacing. Disabled students thus not only lack adequate supportive learning and teaching devices but are also made to use dated equipment. In this research, some participants also raised the issue of out of date supportive gear.

Looking at constraints brought about by university buildings, Mumba (2009) in her study *Students with Disabilities in Zambia's Higher Education System* found that non-conducive environment was one of the constraints that affected the retention and achievement of disabled students in Zambian HE and suggested the removal of such barriers by the provision of financial commitment. The financial commitment involved in providing students with albinism with adequate support was minimal. It basically involved provision of protective gears, the purchase of magnifiers and monoculars, provision of hand-outs and preparation of examination papers in large fonts as well as provision of software that can assist students with albinism with their reading. Although the provision of devices such as magnifiers and monoculars would incur a minimal cost given the number of students with albinism in HE in Tanzania, none of the 14 students with the condition considered in the present study were provided with such support. Magnifiers are devices that enlarge objects and monoculars are devices which allow people with vision impairment, like people with albinism, to see faraway things.

Morley et al. (2010) also found that support rendered to disabled students in HE was minimal. Here they found that teaching and learning materials for disabled students in some universities in Tanzania were inadequate. Tuomi et al. (2015) made similar observations but went further, revealing that their participants had experienced delays in completing their assignments because of slow-functioning or malfunctioning teaching and learning materials. Both Morley et al. (2010) and Tuomi et al. (2015) illustrate the exclusion of disabled students in HE and demonstrate the importance of adequate teaching and learning material for their successful participation. My findings about the impact of inadequate teaching and learning materials on educational participation do not differ much from those of Morley et al. (2010: 95) and Tuomi et al. (2015: 203) and add to the existing literature on disability in HE in a more specific way, that is, including albinism in HE as not much is known in this area.

Negative attitudes towards disability can also constrain the participation of students with albinism in HE, hindering widening participation strategies. Literature from both the Global North and South refer to attitudes towards disability as a structural constraint. This is because when we are different we have a tendency to be labelled as strange (Ahmed, 2000; 2004). People with albinism look different from the African norm. As explained in detail in the introduction and in subsequent chapters, people with albinism have been subjected to name-calling, labelling and discrimination. There have also been mythologies against them. Literature on disability in HE in SSA also indicates oppression and discrimination imposed on almost all people with various disabilities including students with albinism. For example, Chataika (2010), in her study on disabled students in Zimbabwean HE, talks about how cultural negative attitudes, beliefs and values towards disability impacted on their learning. This is an indication that all disabled people in SSA are often oppressed and stigmatised; however, I believe that the experience of people with albinism differs from that of other disabled people. This is because no other disabled group has received the extreme oppression imposed on those with albinism. People with albinism experience the most serious human rights violations, primarily focusing on the ritual killings and attacks (UN, 2013: 3).

2.5 Enablers

Accessing university, according to Canadian researchers Finnie et al. (2008), is a result of complex sets of relationships, including students' attitudes, aspirations and motivation towards HE. Some studies place great importance on young peoples' aspirations and motivation towards the attainment of education and consequently participation in HE (Gorard et al., 2012). This is because disabled students are often faced with physical barriers and attitudinal oppression in accessing or participating in HE. In some cases, disability can affect or restrict peoples' motivations or aspirations for pursuing educational goals. In other cases, disabled people can be subtly advised against aspiring for or achieving their goals or dreams, including participation in HE (Howell, 2006). In Tanzania, for example, in their study on widening participation, Morley et al. (2010) found that some disabled students had been discouraged from aspiring to HE by friends or even extended family members. Such discouragements sometimes need a motivated or aspirational person to sail through. However, little is known about motivations or aspirations as enablers for disabled students to participate in education or even seek degree qualifications particularly

in the Tanzanian context. The commitment to and aspiration for HE revealed by the 14 students with the condition in this study add to such limited data.

The vast literature on disabled students entering and participating in HE often focuses on physical and attitudinal constraints within the HE environment or support in terms of teaching or learning (Fuller et al., 2010). While it is important to also understand the enablers of disabled students in terms of teaching and learning facilities, it is equally important to understand enablers in terms of aspirations or motivations for participating in HE. This understanding is important because it can suggest appropriate interventions for the achievement and retention of disabled students, including those with albinism. This kind of literature is limited and my research attempts to contribute towards filling this gap.

Filling such a gap is important, especially when my research data come from a country in the Global South. I have mentioned elsewhere that data on disability from the Global South, including SSA, are limited; given this, it is essential to add to what is available. De Sousa Santos (1995; 1999 cited by Morley et al., 2010: 21) reminds us that ‘we should have a sociology of absences’. This means that we should also include in our studies those who are often omitted and analyse, rather than simply report, the reasons for the absences. Equally, we are reminded that sociology should strive to minimise any possible doubt in the existing public understanding by allowing other voices to be heard and considered (Back, 2007). My research is meant to challenge the prevailing public understanding of albinism by providing an in-depth case study on the experiences of students with albinism who have received less attention from researchers.

In general terms, students’ motivation or aspirations for HE are linked with economic reasons. Glover et al. (2006), for example, in their study on students entering and completing university education in the UK, found that students’ motivation or aspiration for HE was widely related to economic factors. However, Morley et al. (2010), in their study in Ghana and Tanzania, suggest that disabled students chose HE because they believed it enables them to demonstrate their learning capacity in an environment where they are marginalised and stereotyped as being intellectually inferior. The study also suggests that disabled students aspire to HE because they consider it as a way of mitigating some of the challenges that are often linked with disability, such as lack of financial independence and a negative social identity.

Similarly, a study by Tuomi et al. (2014) found that some women with disability at the UDSM in Tanzania were motivated to aspire to HE because they believed that by acquiring HE qualifications, they would gain value and respect from family members and society as a whole, which would allow them to express their views without fear. The women in the study by Tuomi et al. (2014) reveal how, by being HE students, they were fully taking part in family discussions and decision-making. This kind of positive experience can motivate disabled people to aspire to HE and confirms why some disabled people, like those I interviewed in this research, place so much value on HE. HE to some disabled people is a source of pride, thus answering my third sub-question, which asks what are the motivations for students with albinism to enter HE?

Another study that reflects on the motivation of disabled students in HE is that of Opini (2012). In her study on disabled women in universities in Kenya, Opini (2012) examined their motivation or aspirations to participate in university education. She found that besides choosing HE for reasons of becoming economically independent, the women believed that HE would enable them to become somebody in society (Opini, 2012). Another factor that motivated disabled women in Kenya to pursue HE, according to Opini (2012), was their determination to challenge their marginalised position in society so as to overcome the prejudiced notion of lack. Mwaipopo et al. (2011), in their research paper *Equity and Equality in Access to HE: the experiences of students with disabilities in Tanzania*, which originated from the WPHEGT project, provide evidence that disabled students were motivated by their desire to challenge the prejudice and stigma that is often imposed on them. For disabled people, according to Mwaipopo et al. (2011), HE gave hope of a promising and meaningful future. The factors motivating disabled students, which are discussed in the existing literature do not differ from those expressed by some of the 14 students with the condition considered in this thesis. Given these similarities, this research will add to the literature by providing an in-depth study on the specific disability of albinism. I believe that my research will also contribute to the literature on how students with albinism accomplish their aspirations to HE, particularly because students with albinism are not often given space to discuss their educational life history and agency.

There are many motivation factors. Existing literature show that students' motivation for HE can be enabled by teachers, family members or peers (Gorard et al., 2012). It

is believed that family members can motivate and inspire their children's education through financial or moral support and guidance. De Broucker and Underwood (1998), who conducted an international comparison study on students' intergenerational mobility into HE, suggest that family members, particularly parents, can play an important role towards enabling their children's participation in HE. Ndalichako and Komba's (2014) study on the aspiration of some students in 18 secondary schools in Tanzania also reveals that family and community members, as well as friends, contribute towards motivating learners to successfully participate in education. The contributions are seen in terms of family members' involvement in their children's education (Gorard et al., 2012), expectation of their children's educational attainment (Goodman and Gregg, 2010) and being role models (Eccles, 2009). There is rich literature on students' motivation and aspiration for schooling and even HE but what is limited in this area is specific literature that reflects on family members as enablers of disabled children towards HE participation in Tanzania. The literature that is available, for example Morley et al. (2010) and Tuomi et al. (2015), talks about how family members can influence disabled students' thinking towards their HE participation. Morley et al. (2010) provide a reflection of a disabled student who was inspired by her mother to consider education as a way of minimising social prejudice against her disability. Similarly, Tuomi et al. (2015) in their study which investigated the experiences of being a woman and having disabilities found that one of the enabling factors for the participation of women with disability in HE was encouragement from their family members. My own research reveals that in some cases family members motivated the participants with albinism to aspire for HE, but in others they were seen as barriers.

Family members, as already mentioned, are an important group for any intervention for widening the participation of students with albinism in HE. Aspirations, according to Goodman and Gregg (2000), are often raised early on in a person's life. This could also mean that teachers are an important group in enabling motivation and aspirations for HE. The data indicate that in Tanzania there are currently 24,584 disabled students in primary schools, of whom 1861 have albinism (MOEVT, 2013). If we are to capture this pool for HE then interventions have to start early, with the 1861 pupil with albinism in primary school. This is because 'exclusion from basic education means that there will be a small pool of disabled students qualified to enter HE' (Morley and Croft, 2011: 384).

Other literature in the Tanzanian context, e.g., Ndalichako and Komba (2014), also reveals that teachers were a significant determinant in either enabling or constraining learners' motivation and aspiration. More specific studies, e.g., those of Morley and Croft (2011) and Tuomi et al. (2015), also reveal that teachers' encouragement and support can enable the participation of disabled students in HE. In this research, students with albinism also talked about their teachers at all levels of the education system as people who gave them continuous support and encouragement.

Gorard et al. (2012), who reviewed various literature in the Global North on the attitudes, aspirations and behaviour of young people on educational attainment and participation, suggest that the expectations for HE were mostly formed at the age of 14 years. These findings therefore could suggest the importance of primary and secondary teachers in enabling or encouraging the aspirations and desires for HE by learners if the pool of students with albinism entering HE is to be increased.

I have mentioned elsewhere that the Government of Tanzania, as a developing country, often has limited financial resources to adequately finance HE institutions to provide adequate teaching and learning facilities and a learning environment for a range of users. However, efforts are made to minimise this inadequacy. For example, in 2013, the Tanzania Education Authority (TEA), a government institution responsible for administering the national education fund, financed projects worth US \$454,000. The projects financed were those intended to support the learning and teaching of disabled students in all levels of education. In this context, the TEA provided hearing aids, wheelchairs and white canes and, as regards teaching devices, braille machines, brailion papers, sign language books, TVS and DVD players, and information and communication technology facilities suitable for disabled students (Nyirenda, 2013). The TEA also renovated and constructed classrooms and dormitories in some schools and HE institutions to make them conducive and accessible to all students, irrespective of difference. It also improved the learning and teaching environment of a teachers' college which specialised in training teachers who were to teach disabled students. As for students with albinism in particular, they were provided with sunscreen lotion and sunglasses.

Various literature (Luande et al., 1985; Kromberg et al., 1989; Luande, 2009; Baker et al., 2010) state that people with albinism are often vulnerable to sunburn and sometimes

have a high risk of developing skin cancer, due to the lack of skin pigmentation to protect them from the sun's ultraviolet radiation. Therefore, the lotion and sunscreen provided by the TEA protect students with albinism against these risks. Studies like that of Morley et al. (2010) reveal that poor health can result in some students dropping out of HE. For this reason, the provision of protective gear can improve the health of students with albinism and thus support their retention in all phases of education, including HE. For example, Tuomi et al. (2014) found that assistive devices and other supports provided to their research participants were among the factors that had motivated those participants to progress and continue with their HE. This could mean that a lack of supportive devices is one of the reasons for which disabled students drop out of the education system. In other words, the availability of adequate support contributes to the successful inclusion and completion of disabled students, including those with albinism in HE.

Other literature, such as that by Ezello (1987), a Nigerian scholar who researched the views of students with albinism in a Nigerian university, revealed that the students were experiencing psychological challenges due to social stigma. Given Ezello's (1987) findings, I would say that it is important for HE institutions in Tanzania to have counselling services to improve the retention and achievement of students with albinism. While the study by Morley et al. (2010) on WPHEGT revealed that counselling services were offered in both private and public universities, my research shows that minimal counselling support is specifically offered to students with albinism: although there was a disability support unit at one of my university research sites, it had no provision for counselling. It basically provided sign language services for those who needed them and coordinated the issuing of assistive devices such as braille, or the allocation of readers to students with special needs, such as students with albinism, who often have poor vision. This shows that the provision of readers as a support mechanism was in place for students with albinism although it was only available in one of the four universities which were my research sites. This means that the other three institutions, although they enrolled students with albinism, could not adequately provide support to facilitate their smooth learning.

2.6 Summary

This chapter has looked at some of the literature on disability in HE. Specifically, it has examined literature on the constraints faced, and the support available, to disabled students

in HE, in both the international and the Tanzanian context. The lack of resources to cater for the special needs of disabled students in HE emerged as a clear theme in the various literatures on disability in HE, from both the Global North and South (Riddell et al., 2005; Mumba, 2009; Chataika, 2010; Fuller et al., 2010; Morley and Croft, 2011; Gavira and Morina, 2014; Tuomi, 2014). I therefore concluded that despite ongoing debate about the widening of participation in HE, much remains to be done, especially regarding the inclusion of disabled students. University systems are still among the least inclusive as regards accommodating students' differences in terms of both physical access, and access to curricula (Gavira and Morina, 2014). Although universities are widening participation by including non-traditional students through various admission pathways, the inclusion of disabled students has therefore remained minimal. This is because support for disabled students seems to depend on ad hoc practices, which basically depend on the attitudes and goodwill of the teaching staff (Fuller et al., 2010). This implies that in the absence of sympathisers, students with albinism have limited opportunities to interact with HE.

The next chapter describes my methodology. I will discuss the 'how' of my research as well the epistemological and methodological approaches that were adopted in this thesis.

Chapter Three

Research methodology: ‘The how’: theoretical and ideological beliefs underlying my research

3.1 Introduction

This chapter presents my research methodology. Methodology, according to Sandra Harding (1987), is a theory and analysis of how research is done and should proceed. Ramazanoglu and Holland further define methodology as ‘a procedure for making knowledge valid and authoritative’ (Ramazanoglu and Holland, 2002: 9) and Letherby (2003) sees it as a way of theorising about how we find things out; that is, a relationship between the process and the product of research. In this context, this chapter discusses the philosophical perspectives of my research and provides justification for the approaches and methods I chose in designing the research, and collecting, analysing and interpreting the data.

Although it is now clearly established that there is no single or specific feminist methodology (Stanley and Wise, 1993; Renzetti, 1997), majority of feminist researchers do agree on the ‘the values and principles which are at the heart of the feminist project (Frances, 2002: 52). Some of the values and principles of feminist research, which distinguish it from other social science research, include acknowledging the significance of gender in social life, respecting participants, acknowledging social differences, and aiming for research that is non-exploitative and thus minimises power imbalances (Reinharz, 1992). My research focuses on the experiences of people with albinism who are in HE. As already mentioned in this thesis, these people in Tanzania are an oppressed, marginalized and ill-treated group. I believed, therefore, that an understanding of their experiences of interacting with HE opportunities can adequately be achieved through strong feminist values and principles, as I am interested in both power relations and gender. I believed that such values and principles had much to offer in exploring such complex experiences. In this context, my research drew upon such values and principles and was conducted in ways that can be characterised as feminist.

Although there has been much debate about what constitutes feminist research, my own understanding of it derives from the views of feminist writers such as Ramazanoglu and Holland (2002), as well as Letherby (2003). The former characterise feminist research as that which is saturated with particular theoretical, political and ethical concerns. The latter argues that feminist research can be differentiated from other research by the questions that are asked, the position of the researcher within the research process and theorising, as well as the purpose of the research. I believe that my research embodies the characteristics suggested by both the former and latter, in terms of its ethical concerns, and its aim to investigate gender power relations, location of research, and purpose.

I underpinned this research with feminist epistemological principles. Wilkinson and Morton (2007) pinpoint five epistemological principles of feminist research. They see the first principle as the acknowledgement that gender remains a significant and basic feature of social life. The second is that feminist research should aim at raising awareness of gender inequalities and differences. Third, research should align with post-positivism thus rejecting views of objectivity which assume that grounded experiences are not scientific knowledge. Fourth, feminist research should recognise existing ethical issues by respecting participants and emphasising a balance of power. Lastly, research should stress the change in women's conditions and advocate the dismantling of patriarchal structures.

Underpinning my research with the above principles, I also draw upon the principles of African feminism. Mama (1995) an African feminist scholar informs us that African feminists can design their research using research principles and methods drawn from non-African feminist theorists by improvising and modifying them to African usage. Here, Mama (1995) suggests that an African feminist researcher, for example, using semi-structured interview methods to gather information in a community with which she is familiar, can modify methods adopted from the non-African context to fit the cultural knowledge familiar to the African feminist. In my case, I applied Wilkinson and Morton's (2007) principles, keeping in mind my African principles and values, which I am familiar with.

Drawing upon these epistemological principles, I embarked on this study with an aim of conducting research which would give female students with albinism a voice. I later realised, however, that there were some questions that I could not answer or make

policy recommendations for if I did not involve the female students with albinism's male counterparts. I therefore decided to design research that would also involve male students with albinism as well as other male participants. Firstly, this was because the aim of my research was to bring to the surface the voices that are widely excluded from HE. Secondly, the aim was also to raise awareness of existing socio-cultural differences, including disability and gender differences in the education sector and in particular in HE, and also within Tanzanian society in general.

3.2 My research design

Research design, according to Merriam, is a 'plan for assembling, organising, and integrating data, and it results in a specific research findings' (Merriam, 1988: 6). Feminism does not advocate any specific research design or approach. Instead it argues that different designs or approaches may be adopted to explore different realities in societies depending on the respective research questions under study (Ramazanoglu and Holland, 2007).

My research questions, which I have listed in the introduction section, called for a design that celebrates depth, context, richness, multi-dimensionality, nuance, and complexity in research (Mason, 2002). Qualitative research design, according to Mason (2002), could achieve all this. Holloway (1997) describes qualitative research as a form of social enquiry that focuses on the way people interpret and make sense of their experiences and the world in which they live. Creswell (2013) provides a new definition and suggests that qualitative research is a situated activity that positions the researcher in the world. This kind of location provides spaces for oppressed voices to be listened to by allowing them to convey their stories in their own words (Letherby, 2003). Here Letherby (2003) sees qualitative research as having the potential to capture the complexity of our lives and our different perspectives. This way, I found qualitative research to be a more suitable design for this particular research as my intention was to provide people with albinism in my research with a voice, as well as to capture the nuances in their lives that constrain or enable their participation in HE.

Theoretically and conceptually, as mentioned elsewhere in this thesis, there is limited knowledge about albinism in HE. Different case study theorists suggest that in situations where theoretical knowledge is limited and under-explored, a case study is suitable for

generating in-depth exploration of the phenomenon, as it provides rich description and understanding of the case under study (Merriam, 1998; Yin, 1994, 2003, 2013; Stake, 1994, 1995). In this context, this research adopts a case study approach to provide a detailed in-depth exploration of the phenomenon of disability in HE. I used students with albinism as specific cases to explain the phenomenon. The well-known case study researcher Stake (2006) sees cases as bounded systems that comprise a complex of interrelated elements or characteristics that clearly have identifiable boundaries. In this research, the distinctiveness of the cases studied was constituted by the subjects being students with albinism participating in HE in a Tanzanian university. My cases were multiple although in the analysis each case was treated singly. This design allowed an in-depth comparison and contrasting of cases, as well as showing different perspectives on disability in HE (Creswell, 2013). Here, as already mentioned, my unit of analysis was albinism.

There are different ideas and some disagreement on what constitutes the term ‘case study’. For example, another well-known case study researcher, Yin, sees ‘a case study as an empirical inquiry that investigates a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident’ (1984: 23). Stake further suggests that it is ‘defined by interest in individual cases, not by methods of inquiry used’ (2003: 134). For Merriam, a case study is ‘a basic design that can accommodate a variety of disciplinary perspectives as well as philosophical perspectives on the nature of research itself (1988: 7). But what these three theorists of case study tend to agree upon is that a case study is a collection of methods to investigate a complex phenomenon with specific bounded systems. Having discussed my research design I now turn to discuss how I collected my data.

3.3 My data collection process

At an early stage of my research, I submitted an ethical application for the scrutiny and review process. This meant that I could not begin my fieldwork until the application was approved. However, while waiting for my ethical clearance, I carried out a desk-based research methodology to collect data so as to answer my first sub-question as shown on section 1.2. From the preliminary data, I established that in 2013, out of the 20 students with albinism were located in 12 of the 52 registered universities in Tanzania (TCU, 2013)

where they were undertaking different degree programmes. Due to time and financial constraints, I chose four of these 12 universities as the site of my fieldwork, two being institutions with supportive devices and thus able to admit disabled students; and two which could not, due to their lack of such support. The rationale behind this decision was that these four universities had more than one student with albinism and overall had a total of 11, which was more than my planned sample size of eight students with albinism. One university had four students with albinism, another three and the other two universities had two each. Nine students were thus in institutions which could support disabled students, while the rest were in institutions which could not.

To adequately answer my first research sub-question, I first drew on secondary sources, which contain student statistics generated by various institutions. Given this research technique, the study at first entirely relied on data posted on the websites of the 52 registered universities in Tanzania in 2013. However, as I have mentioned elsewhere, HE student statistics in Tanzania rarely give the numbers of disabled students. Having failed to obtain a reliable number of students with albinism enrolled in HE, I opted for the research technique of making informal telephone calls, ringing the 52 staff responsible for institution statistics.

Carr and Worth (2001) argue that telephone interviews can be a handy data collection tool. They believe that such techniques are useful because they allow researchers to easily access widely scattered participants and can be cheap and quick to carry out. Naturally, it often depends on whether the participants have access to reliable telephone services. In Tanzania, mobile telephone services are widespread, and thus easily accessible and available even in remote rural areas. The existence of such telephone services made it easy for me to access the statistics officers of the 52 universities, which were scattered countrywide. Tanzania is a big country with a total of 885,800 square kilometres of land area.

Having obtained the telephone contacts of the respective institutions from the websites, I sought a series of informal telephone interviews with the respective staff. This method allowed me to talk informally to the 52 participants. The main question I asked during this informal telephone conversation was whether the institution had any registered students with albinism and, if so, how many. Getting answers to such questions was not easy as

most of the officers required time to search for the data. In some cases, it took me several phone calls before I could be given an answer. From this, I realised, as mentioned in Chapter Two that students with albinism were rarely tracked down. For this reason, they end up being treated in the same way as all other students (Morrice, 2013a).

After collecting data through the desk-based research on in which universities students with albinism were studying, I proceeded to begin my fieldwork. Although I was aware of where students with albinism were located in Tanzanian universities it was not easy to access them. People with albinism in Tanzania live in fear and are subject to constant threats because of the killings and amputation of body parts as explained in the introduction. These killings do not only cause suspicion of any person wishing to talk to people with albinism but also mean that people with albinism are often reluctant to talk to strangers. Suspicion and reluctance could sometimes make a study run into trouble due to lack of cooperation from the targeted group. In this case, every effort was needed to minimise suspicion and reluctance and win the trust of students with albinism. Creswell points out that we can use ‘gatekeepers or key informants’ to assist us in accessing participants (2007: 71). I therefore had to negotiate access through gatekeepers who had already won the trust of people with albinism. My aim here was to negotiate through respective universities. My fear was that negotiating through gatekeepers in residential areas could delay my data collection or even affect the entire research process. This was because accessing them from their residential areas was challenging and difficult because of frequent reporting in local and international media about their brutal killings and amputation.

Before and during my data collection some newspapers carried headlines such as *Crackdown on witchdoctors after albinos killed to harvest body parts* (Soares, 2008) and *Albinos in East Africa Fear for Lives After Killings* (Omolo, 2009). Other such headlines were *Africans with Albinism Hunted: Limbs sold on Tanzania’s black market* (Chang and Diaz, 2010) and *Rukwa on alert as thugs chop off albino’s hand* (Siyaame, 2013). With such threatening and screaming headlines it was challenging for a stranger to approach a family or community gatekeeper asking to research students with albinism’s life experiences, even though Carol Smart (1984) assures us that a woman researcher is often trusted and seen as less threatening. It would need a lot of courage for a family gatekeeper to allow even a woman like me to access student with albinism with such life-threatening situations. In my personal capacity, therefore, the process of trying to secure

research access was stressful as it caused feelings of insecurity, fear and anxiety as to how I would be received and responded to.

3.4 Gatekeeper negotiation process

Given that it was challenging to access students with albinism from their residential areas, I negotiated their access through university gatekeepers. I submitted my letter of request to the four universities and made phone-call follow-ups. The students in question were then contacted and informed about my research and my intentions to contact them and I was given the phone numbers of various students with albinism for soliciting and recruiting. I contacted the students and six of them agreed to participate. I had to travel to conduct the interviews with those who lived outside Dar es Salaam as I was aware that in some cases doing research in participant's own space usually makes them feel a sense of control (Letherby, 2003). One of the participants residing outside Dar es Salaam, however, preferred that the interviews be held in Dar es Salaam and came for the interview. I respected her decision given that 'when doing sensitive issues, participants may sometimes not feel comfortable when the research takes place in their own environment' (Letherby, 2003: 108).

In accessing participations I did not only use a gatekeeper but also I used snowballing through some participants to recruit others. One participant was recruited in this way his name and contact details were given to me by another participant. The student whom I recruited through the snowballing technique was undertaking postgraduate studies outside Tanzania, but had undertaken undergraduate education in the country. I corresponded with this student by Skype. My experience with this Internet method of data collection was that there was limited rapport between us when compared to the face-to-face interviews or focus group discussions that were used elsewhere in this research.

The access to graduate with albinism differed from that to students with albinism. In the process of my research I came to learn from students with the condition that there were a number of graduate with albinism at one NGO that deals with the wellbeing of people with albinism. This therefore meant I had to go through the NGO gatekeepers to access the graduate with albinism. I knew nobody at that particular NGO so I searched for the location address so that I could visit the organisation. My intention here was to be

introduced so that I could win the trust of the graduate with albinism. I therefore prepared my research documents and headed to the NGO's office premises. When I arrived at the premises I was faced with an office surrounded by a tall wall with electrical security wire. I could not see what was inside the tall wall so I decided to knock on the gate. A gatekeeper opened a small window and asked what I wanted. Peeping through that small window I could see another gatekeeper holding a rifle. I could also see a traditional weapon known as *rungu* near the guard who was asking me questions. A *rungu* in the Kiswahili language is a wooden throwing weapon often associated with Maasai male warriors who use it in warfare and sometimes for hunting.

Still outside the gate, I was then asked whether I had an appointment or if there was a particular person that I wanted to meet. I did not know anybody so I told the gatekeeper about my research and that I wanted to meet the head of the organisation. After my explanations the gatekeeper with the rifle on his shoulder opened the gate and I was let in. As I walked towards the office building I was stopped and asked to come back for screening. I was then screened with a metal detector device. Having been found harmless I was given permission to proceed to the reception office. Before proceeding, however, I was asked to leave all my belongings including my handbag and mobile phone in a drawer and the drawer was locked and I was given the key. As I needed to introduce myself and recruit participants, I asked if I could take the recruitment letters and information sheets with me. The gatekeeper accepted my request but this was after the letters were scrutinised to ensure safety. The whole process evoked Sara Ahmed's (2004a) notion of the politics of fear.

In her notion of politics of fear, Ahmed (2004a) talks about how people who appear Middle Eastern, Arab or Muslim are sometimes feared and designated as terrorists. In this context, it appeared that the NGO I visited designated some people, as fearsome. While Ahmed (2004a) links the terrorist fear with the events of 11th September 2001 in New York, I assume the NGO links their fear with events such as '*African with Albinism Hunted: Limbs sold on Tanzanian black market*'. Such fears made me very uncomfortable, particularly when entering the premises of the NGO. I am not sure whether it was my imagination but I could see a look of suspicion in the eyes of the gatekeepers. This made me sad because I was worried whether I would develop a good rapport, given that in the view of the NGO and its staff I was 'already recognised as a stranger posing danger to

property and person' (Ahmed, 2000: 32). Sara Ahmed (2000) pinpoints that what makes us different is how we inhabit space. Being a person without albinism, therefore, I was already recognised as not belonging, given that the space of the NGO in question was already occupied by people with albinism.

This kind of worry triggered my imagination to feel that fear and hatred in the context of albinism, as will be explored in detail in Chapter Four, was a vicious circle: circulating towards albinism, then bouncing back toward those without albinism. I also felt that the power relations in this vicious circle were fluctuating depending on domination. At the very NGO where people with albinism held the dominant power, I basically felt vulnerable. However, I encouraged myself to proceed to the reception office because my desire was to support change of the vicious circle of fear and hatred.

To my surprise I was cordially received at the reception office. When I explained the intention of the visit, a gatekeeper at the reception called another gatekeeper for further discussion. I again explained about my research and the gatekeeper suggested calling me back to agree upon dates for the interviews with NGO officials and the focus group interview with graduates with albinism, which I had requested. When the interview dates were set I visited the NGO and went through the same procedures of being scrutinised with a metal detector. This time, however, the discomfort and anxiety had eased as I had already built trust with the would-be participants of my research project. Thus I conducted interviews with two officials at this NGO and held a focus group interview with seven graduates with albinism, which were among the most enjoyable and friendly interviews I carried out during this research.

Having completed interviews at the above mentioned NGO I visited another NGO that is also responsible for the welfare of people with albinism. Surprisingly, the gate of the second NGO was wide open; there were no guards and people could come and go as they please. Even when I arrived at the office building of this second NGO the entrance door and individual office doors were all wide open, allowing in fresh air. Here there was no physical gatekeeper to go through so I introduced my research and myself. Two officials at this NGO agreed to participate, we set the interview date and time and the two officials - one with albinism and one without - were interviewed separately.

Permission to access support and teaching staff as well as the student reader (a student who assists students with albinism with their reading and note-taking) was sought and granted at the same time as that to access the students with albinism. Members of this group were then contacted and recruited individually. Thus the six teaching staff and five support staff as well as one student reader who participated in this research were chosen on the grounds of convenience, contrast and their willingness to participate. However, for the teaching staff a key criterion for their selection was having taught students with albinism. As for the government officials, every effort was made to include those who were responsible for education policies, particularly on disability. The four government officials were solicited through word-of-mouth but this was after going through the gatekeeper in the ministry responsible for education. Here a letter was submitted explaining my research, and after signing and committing myself that upon successful completion of my PhD I would make available a copy of my findings for policy purposes, the permission was granted.

One of the participants to whom I had access during this research was the mother of children with albinism whom I had known for more than ten years without knowing about her children's condition. It was only when I started this research that I came to know about that from other participants. Although it is not always the case that people talk about their children to everybody, in the interview the mother mentioned how she had lost some friends after she had given birth to children with albinism. For this reason, I assume that mother of children with albinism might have found it difficult to talk about their children because of the social shame which circulates around albinism, or because of their fear of isolation. I had intended to interview another mother of children with albinism whom I have known for years but I could not easily contact her because she had travelled to a village outside Dar es Salaam where the mobile telephone network was poor and not easily available.

3.5 My interview process

Although Kelly et al (1994) suggest that feminist researchers should not consider interviews as orthodoxy, feminists, according to Maynard (1994), often prefer using interviews because they produce the kind of knowledge of lived experiences that feminists wish to make available. My choice to use interviews lies in my ontological position, which sees the experiences of students with albinism as meaningful properties of social reality. This way,

I believe that a meaningful understanding of students with albinism's life experiences is gained through interactive talking with them. My preference for interviews was also due to their potentiality to allow in-depth understanding of the phenomenon as well as their flexibility (Hesse-Biber, 2007). Again because of my feminist values and principles, my interests were in a method that allows a democratised process and reciprocal obligations between participants and myself, and interviews often provide such processes adequately. In this context, I chose to have three types of semi-structured interview techniques, namely individual, Internet and focus groups.

Semi-structured interviews fitted this research best because my interest was for any research technique that would allow themes to emerge from the data. I conducted individual face-to-face semi-structured interviews with 20 participants. Each participant was interviewed once, except for two students with albinism who were interviewed twice: once at the very start of the fieldwork, and again at the end. This was not only to allow more rapport with the two participants but also to explore issues which had remained unclear in other interviews. These individual face-to-face semi-structured interviews enabled me to investigate in-depth the life experiences of students with albinism. As already mentioned above I also had one Internet semi-structured interview with a student outside the country.

In addition to individual face-to-face and Internet semi-structured interviews, I also conducted focus group discussions. Kitzinger (1994), a renowned scholar on focus group research methods, suggests that focus group interviews are especially helpful when one is researching difficult participants. For Kitzinger (1994), difficult participants are those who are marginalised or stigmatised, or feel unsafe. As already mentioned, people with albinism in Tanzania are murdered or injured for their body parts and can thus be categorised as difficult participants as they are likely to feel unsafe in the presence of a stranger like myself. For this reason, I believed that my participants with albinism would feel more safe, comfortable and relaxed in a group research study. I therefore chose focus group interviews with the anticipation of minimising the sense of insecurity that those participants with albinism might experience.

A number of writers have made useful suggestions in relation to focus group interviews. Patton (1990), for example, suggests that such interviews are efficient ways of collecting

qualitative data. Another scholar on focus group methods, the American feminist Montell (1999), informs us that we can strengthen and broaden our feminist qualitative research by using focus group interviews. Having reflected on such viewpoints, I drew upon focus group interviews in order to strengthen and diversify my research methods.

In terms of the number of participants in focus group, Krueger (1994; 2000) and Morgan (1997), who are among well-known scholars of focus group research techniques, tell us that we can collect enough research data from three to six different focus groups. In his earlier writing, Krueger (1994) suggested that a well-designed focus group interview could involve six to 12 participants. However, in his more recent literature, Krueger, in collaboration with Casey (2000), argues for a focus group incorporating six to eight participants. Following Krueger's (1994) recommendation, I decided upon having three different focus group interviews: one with three teaching staff; another with four support staff; and a third with seven graduates with albinism.

Given my feminist principles and values, my intention was also to address the power dynamics that can occur in my research. This way my wish was to draw upon interview techniques, which would minimize the power imbalance. Kitzinger (1994) and Montell (1999) inform us that focus group interviews are often non-hierarchical and they often allow democratic practices and balanced power between participants and researchers. For this reason I chose focus group interviews for purposes of achieving my feminist democratic principles and values of minimizing power hierarchies and exploitative trends. Another reason for choosing focus group interviews was that they have the potential to enable members of the group to feel a sense of collective identity and solidarity (Kitzinger, 1994).

As I have indicated in previous chapters and as I will elaborate in the chapters to come, students with albinism are often victims of hate. According to Matsuda (1993), victims of hate are widely subjected to fear and a sense of self-hatred. When members of a particular group experience a sense of self-hatred, it can result in a loss of a sense of collective identity or solidarity. Therefore, when involving such groups in research, it is important to design a study which creates a sense of collective identity and solidarity. Focus group interviews are seen as appropriate research methods as they can allow participants to feel a sense of collective identity and solidarity (Kitzinger, 1994). Furthermore, focus groups

often have the potential to stimulate participants' memories because to a large extent members of the group learn from each other, and exchange and build on each other's views. This, in a way, can make participants experience the research as an enriching encounter. In this research, for example, the seven graduate with albinism talked about how they had benefitted and learnt a lot from each other. On my side by using focus group discussions, I generated richer and more in-depth data in relatively shorter periods, because 'the most obvious reason for interviewing in groups is cost and speed (Hedges, 1985: 71).

Hesse-Biber (2014) suggests that we can use topics as our lines or domains of inquiry to conduct interviews. In terms of semi-structured interviews, she sees an importance of having a specific guide, which has written questions that will be covered in a particular interview. This way, I prepared an interview guide, which had particular topics. In each topic I had a list of questions that I discussed and covered with all the participants. In the very interview guide I had a set of points to start the discussion with participants. As already mentioned above, there were eight different groups of participants, which were: seven students with albinism, seven graduate with albinism, six teaching staff and five supporting staff. Others were four NGO officials, four government officials, a parent and a student reader. So each of the eight groups had its own specific list of topics and questions that were covered in interview sessions.

There were, for example, nine topics for the group of students with albinism, graduate with albinism and a parent. In these groups, the nine topics covered were family, earlier education experiences, motivation, university entry and transition, experiences of the course, support services, aspirations and policy recommendations. For the group of teaching staff and a reader, the four topics covered university life, experience of the course, support services and policy recommendations. In terms of the group of support staff, government officials and NGO officials, the topics were university life, support services and policy experiences. The topics and questions thus differed in context between each group (see Appendix II to X).

While topics differed in each group, my probe questions depended on how the discussion was going in each interview. Here I kept in mind Hesse-Biber's (2014) point that probes are for providing participants with support and encouragement. I therefore made my probes

different ways of making the participants continue talking. However, being a feminist researcher, I made sure that I did not go against feminist principles and values and drew upon the probing interview techniques suggested by the feminist scholar, Hesse-Biber (2014). Hesse-Biber (2014), besides suggesting a technique of asking probe questions in an unbiased way, pinpoints techniques such as nodding or maintaining eye contact with participants. By probing, my intention was to seek more in-depth insights and thus elicit participants' perceptions and opinions as to the experience of students with albinism in interacting with HE opportunities.

I introduced the topic with commonly-used openers such as: Tell me a bit about? Do you have? or What would you say? This way I allowed participants to talk freely but I used probe questions to direct the conversation to issues, which were essential to my study (Hesse-Biber, 2007). Here, of course, I tried to avoid any leading or loaded questions. Some such probes were snatches of conversations or chats making the interviews like a more natural conversation (Hesse-Biber, 2007). The probes were important, as my intention was to compare the similarities and differences in the participants' reflections.

Interviews were conducted in both English and Kiswahili. The reason for this was that both English and Kiswahili are used in Tanzania. English is an official language whereas Kiswahili is the national language and is mostly used by the majority of the people. Thus four of the seven students with albinism chose to use Kiswahili while the rest decided to respond in English. In relation to the seven graduates with albinism, one government official and one member of support staff responded mainly in Kiswahili but some of them would occasionally use English words. All six teaching staff and four support staff members, three government officials as well as two NGO officials and the parent used English whereas two NGO officials and the student reader responded in Kiswahili. By the use of Kiswahili I had to translate the data to the language of research which was English.

Temple and Edwards (2002) refer to research which uses translators as cross-language research. In cross-language research Twinn (1998) thinks it is important to interview participants in their first language, particularly when a researcher has access to the same language as the participants. She believes that such an approach improves the rapport between participants and researchers. Twinn (1998) also suggests that the use of the language with which participants are more familiar enables them to easily narrate their life

stories and experiences. One explanation for this is that many of the original experiences and beliefs were conducted in the first language. For example, Madriz (1998) found that by interviewing Latina women in the USA in Spanish, she increased rapport as more women responded to her research.

Like Twinn (1998) and Madriz (1998), Temple and Edward believe that interviews are ‘processes which establish shared background and understanding’ (2002: 15), thus emphasising the use of the participants’ language as a possible means of increasing rapport between researchers and participants. Given these perspectives, I felt that interviewing participants in Kiswahili would create a sense of common experiences and viewpoints, and would thus improve rapport and, consequently, level the power imbalance that existed in my research, as discussed in the section below.

Although some literature (Twinn, 1998; Madriz, 1998; Temple and Edward, 2002) pinpoints the advantages of using a first language in cross-language research, other literature gives a list of ethical and methodological challenges to conducting interviews in cross-language research (Tsai et al., 2004; Squires, 2008). Ethical and methodological challenges, according to this literature, relate to ensuring the translated transcripts deliver the same meaning and maintain relevance in the original language and the study language because error in the translation can misrepresent and distort research data or findings. According to Tsai et al. (2004), such challenges occur because in the process of translation there are possibilities of compromising an in-depth analysis which would affect the rigour of the findings. Likewise, the quality of research data can be affected by the translation process because ‘some languages may not have a conceptual equivalence in the language into which it is to be translated’ (Bassnet, 1994 cited in Temple and Edward, 2000: 5).

However, in minimising data distortion, Birbili (2000), in her article *Translating from one language to another*, suggests that translators should be competent in both languages. Gee (1992) also suggests that translators should have language competence when providing translation services. Furthermore, Liamputtong (2008), in her book *Doing research in a cross-cultural context: methodological and ethical challenges*, also argues that translators who understand participants’ culture and language are more likely to minimise potential threats to the rigour of research data as they are more aware of nuances embedded in cultural and language expressions. This could mean that by being born and growing

up in Tanzania I had a better chance of understanding the culture and language of the participants in this study, and thus of minimising possible threats to the rigour of my research.

Vulliamy et al. (1990) and Birbili (2000) support a methodological approach in which the researcher and the translator are the same person. However, Vulliamy et al. (1990) go on to say that when the researcher and the translator are the same person, the quality of translation will highly depend on the researcher-translator's knowledge of the language and the culture of the participants in the study (p.166). This means that, as researcher and translator, the quality of translation in my research depended on my knowledge of Kiswahili and Tanzanian culture. As I have mentioned above, as a Tanzanian by birth, I am conversant with the Kiswahili language and am also familiar with Tanzanian culture, as well as the English language. I have been using both English and Kiswahili for a number of years. These factors contribute to the quality of my translated data.

Cross-language research requires a researcher to have in place mechanisms which will minimise the challenges of misinterpretation and distortion of meaning. In order to minimise possible challenges, therefore, I thoroughly reviewed each translated transcript so as to ensure that the transcripts were accurately translated. When some Kiswahili words had no equivalent meaning in English, I searched for different possible meanings by using the Google translation software. This approach was to identify the best words suitable to convey the participants' meanings. In so doing I typed the word or sentence in Kiswahili and the software would provide me with the most accurate translation in English. In addition to typing words and sentences in Kiswahili in the Google translation software, to further confirm the accuracy of the translation as well as to check any possible errors I also used a back-translation approach. Words and sentences translated into English were entered into Google translation software to obtain a translation in Kiswahili. My intention here, as mentioned above, was to maintain the original meanings that participants constructed about the social world (Coad and Lewis, 2004). Nevertheless, I hope to have maintained the tone and integrity of the original interviews.

Some interview sessions took longer than anticipated. For some of them I felt that the participants were experiencing them as a 'tell it all', or confessional events (Watts, 2006: 398). Three individual interviews and one focus group interview lasted for more than 180

minutes. This was an indication of a good rapport, thus challenging my earlier assumption that the students and graduates with albinism might be reluctant to participate in the research or even to answer some questions because of the harassment and abuse that they often endure. But contrary to such assumptions all 14 people with albinism in this study were eager and willing for their voices to be heard and thus talked in-depth about their life experiences.

In her book *The Art of Storytelling*, Mellon (1998) reminds us that in all human beings there is a natural urge and ability to tell stories. During the interview sessions, I could sense just such an urge and ability in all the 14 students with albinism and was pleased that I had recruited participants who were willing to share their stories (Creswell, 2007). In the focus group, for example, most of the participants wanted to say something about themselves and their experiences. For example, in a graduate with albinism focus group interview one member said ‘can I say something because if I don’t say it I won’t be comfortable’. The interview thus satisfied their deep desire to tell their stories, which I believe we have silenced for a long time.

The eagerness of some of the 14 people with albinism to tell their stories made the interview processes labour-intensive, due to a sense of affective load. Nahl, who has written extensively on behaviours of information-searching, defines affective load as ‘a sense of uncertainty brought about by a feeling of time pressure during the process of searching for information’ (2004: 191). For Nahl (2004), uncertainty can result in feelings of irritation, frustration, anxiety and anger. Given this, for the searcher to continue searching for information until something substantive is found, Nahl (2004) believes the searcher must be motivated to the end of the search. In this research, interviews varied from 45 minutes to more than 180 minutes but, despite experiencing different feelings of extortion, I continued searching for information.

Although my research plan was to end the interviews when all topics had been discussed, or when at most 90 minutes had been reached, some interviews went beyond the set time because some of the participants wished to continue to talk about their experiences. I was aware that some therapeutic benefits could sometimes derive from interviews (Phoenix, 1994; Watts, 2006). Some women in Phoenix’s (1994) research, for example, found interviews were an opportunity to share their problems with somebody. This research

appears to have been an opportunity for the students with albinism to share theirs and thus minimize loneliness.

As already mentioned, my primary wish was to bring to the forefront the agency of people with albinism, who are often silenced and marginalised in HE spaces. Thus, I aimed to give students with albinism an opportunity to share stories of their extraordinary agency so as to remove albinism from the sticky victimhood discourses and attach it to a discourse of agency. The most appropriate way to accomplish my aim, I believed, was to allow the students in this research, particularly those in focus group discussions, ample time to tell their stories and lived experiences. Given that most research methods, including focus groups, are often developed in the Global North, as mentioned in section 3.1, Mama (1995) advises African scholars like myself to modify the methods to fit our local contexts.

Likewise, Krueger and Casey (2009) advise researchers using focus group discussion methods in cross-cultural research to conduct the discussions in a way that is suitable to the cultural context of the research. In the same spirit, Stewart et al. (2007) caution researchers using focus groups to be aware of the possible impact of culture on the method. They warn us that, because culture can influence human behaviour, focus group methods may not work equally well in all cultures. However, Jakobsen (2012), who conducted focus groups in Tanzania, believes that focus groups are appropriate methods to be used in the Tanzanian context. Nevertheless, she believes that they need to be strengthened to fit the Tanzanian context and culture.

Given the strong oral traditions in African countries like Tanzania, (Mbiti, 1989) in which people take time to tell their stories, the ninety-minute focus group discussions often suggested by scholars from the Global North (Kitzinger, 1994; Krueger 2000, Krueger & Casey, 2009) may not be appropriate in the Tanzanian culture and may thus require some modification. For example, in sub-Saharan African, including Tanzania, time works differently than in the Global North and the guidelines for optimum time for focus groups often have norms that are related to the countries of the Global North. Thus, I had to modify the timing of some of my focus group discussions to go beyond ninety minutes. Some people in the focus groups came and left the discussion, as some had to go to mosque. Given these circumstances, there were different time relationships, which made completing a complex discussion in ninety minutes difficult.

Quite a number of people with albinism who heard about this research subsequently wanted to participate. For example, when I went to interview one of the participants I found that he had lined up 12 other students with albinism for a focus group interview. This was an ethical dilemma on my part, firstly because the students attended secondary school and secondly because they were children between the ages of 12 to 16 years. My dilemma was that there was an age restriction of 18 years but there was also a feeling of guilt for ignoring and silencing the voices that were eager to be heard. Despite the guilt I could not involve the children because the research was neither designed nor ethically cleared to involve participants under the age of 18 years.

Miller and Bell inform us that ‘the course of a project may only be guessed in the initial stages’ (Miller and Bell, 2002: 54). This could mean that research is messy and therefore can be redesigned. In my case, I redesigned my research not to include children with albinism but to include a representative of children with albinism, in this case a mother of children with albinism. On this basis, the section on mothers of children with albinism in Chapter Five is meant to allow the voices of children with albinism to be heard. This is because ‘feminists should enable the voices of others to be heard’ (Wilkinson and Kitzinger, 1996: 20).

3.6 Interview recording and transcribing

In this research all interviews were audiotape-recorded after all participants had agreed. Thus I took very limited notes. Of course, I was aware of the importance of note-taking. I believed that by taking notes I would show the participants that I was interested in what they were saying. Such a move was meant to keep them alert and motivated. But the ultimate aim of my study was to include the voices of marginalised people through quotations. To do so effectively and accurately meant that I had to capture the exact words of the participants. I could only do this successfully by using an audio recorder.

Another reason that prompted my use of an audio recorder was that in order to successfully conduct a feminist research, one needs to develop rapport with participants. A good rapport, I believe, can be developed through eye contact with the participant. For me, effective eye contact cannot be achieved when one is busy taking notes. Therefore, I successfully maintained eye contact with my participants and allowed careful listening

and prompt questioning. Creswell (2007) advises us to be prepared with follow-up or prompt questions, so that we can obtain optimal responses from participants. Listening carefully to what the participants were saying thus enabled me to raise prompt questions when the need arose. Basically, this was made possible because I used recorded interviews rather than taking thorough notes.

I was aware that some people are sometimes threatened by the use of audiotapes. According to Hesse-Biber (2007), people worry because it is believed that their recorded statements can sometimes be used against them. In this research, as previously stated, all participants agreed to be audiotaped. This meant that I had to transcribe all the interviews. Evers (2011) and Krueger (1994) see transcript-based analysis as the most rigorous and time-consuming data analysis exercise. Hammersley and Atkinson (1995) estimate that the time of transcribing a one-hour interview can be five hours. Likewise, Bryman (2001) suggests that one hour of recorded tape may take five to six hours to transcribe. Evers (2011) agrees with Bryman (2001) and points out how tedious transcribing can be. She states that the task can take approximately four to eight hours for a one-hour interview. In my case, the exercise of transcribing interviews, which ranged from 45 minutes to 180 hours, varied from four to more than eight hours. Showing that the transcribing of my data was laborious.

The process of transcribing was not free of challenges, particularly when I was transcribing focus group interviews. A particular challenge was identifying individuals in the discussion, which required me to replay the tapes several times so as to grasp the voices of group members. I then spent hours putting the transcripts together and thus ended up with a mass of written data. According to Krueger (1994), transcript can result in 50 – 70 pages of text. The focus group interviews with the seven graduate with albinism, for example, yielded 119 pages of text. I therefore had to arrange, analyse and summarise them thematically (Hammersley and Atkinson, 1995).

3.7 Ethical issues and considerations

Renzetti and Lee remind us to anticipate ethical issues, particularly in sensitive research. They define sensitive research as that in which there is substantial threat to those involved as participants and researchers (1990: 511). Although this particular research focused on

disability in HE, I approached it with caution, because of ‘its threatening characteristics and possible negative consequences for both the researcher and researched’ (Renzetti and Lee, 1990: 512). This research also involved participants with albinism who are ethically characterised as ‘vulnerable’. Ethical issues were therefore taken strictly into consideration as I wished to collect quality data (Ellsberg et al., 2001: 4)

As mentioned above I began my fieldwork after submitting an application and receiving ethical clearance. The process of gaining ethical clearance gave me a good opportunity to thoroughly prepare for fieldwork by requiring me to prepare information sheets, recruitment letters, consent forms and interview guides. Notwithstanding such preparations a number of ethical tensions and dilemmas arose in the course of the research process suggesting that:

(t)he complexities of researching private lives and placing accounts in the public arena raise multiple ethical issues for the researcher that cannot be solved solely by application of abstract rules, principles or guidelines. Rather, there are inherent tensions in qualitative research that is characterised by fluidity and inductive uncertainty, and ethical guidelines that are static and increasingly formalised (Birch et al., 2002: 1).

I was aware of the ethical complexities of researching peoples’ life experiences but I was confident because I embarked on this research guided by feminist values and principles as well as by the ethical principles and considerations outlined in the ESRC Research Ethics Guidebook (2011). The 35 participants were each required to sign a consent form in order to take part in the research. The informed consent form (see Appendix XI) provided information about the nature and modalities of the research as well as a provision for signing to indicate agreement to participate. Out of the 35 participants only one of them could not give written consent. The participant in the group of NGO officials verbally agreed to take part but could not sign the form because it was written in the English language, which he could neither read nor understand. In this context, gaining written consent from the participant was challenging. McCaber (2005) and her colleagues suggest that the process of gaining formal consent, particularly written, can sometimes lead to embarrassment, confusion and misperceptions.

According to McCaber et al. (2005), consent forms can discourage participation. For this reason, I apologised and assured the participants of my understanding, but indicated the

importance of his consent to take part in the research. The participant then opted to give his verbal consent in Kiswahili through a recorded audiotape in place of written consent. Certainly written consent is established as the foundation of research ethics. But Ellsberg and Heise (2005), who draw upon experiences of ethical issues from researchers in 40 countries, remind us as researchers that sometimes we need to adapt ethical guidelines on the basis of our local settings. In this context, I decided to adapt on the basis of the Tanzanian context where the majority of people do not understand well English.

Some people may well be surprised by my statement that the majority of Tanzanians are less than fluent in English, and by the use of Kiswahili in some of my interviews given that the medium of instruction in Tanzanian secondary schools and HE is English. However, it should be remembered that the majority of Tanzanians attended or attend public primary schools where all subjects, except for the English language, are taught in Kiswahili. Moreover, for a large number of Tanzanians daily communication is often carried out in Kiswahili. This makes Kiswahili a well-understood and easy language of communication when compared to English.

Other researchers who have carried out research in Tanzania have also suggested that the majority of Tanzanians lack proficiency in English. Morley et al. (2010), for example, inform us that during their interview sessions some students, particularly those in private universities, demonstrated their lack of English language skills. I understood and respected this reality, and the participants' requests to use their national language. By so doing, I wanted my research to stick to its feminist principles and values and also for it to be experienced as feminist research (Morley, 1996). Despite several attempts to minimise the power and privilege that I had as a researcher, some powers in this research were inevitable. Given that many of the experiences and beliefs that were described by students with albinism would have been in Kiswahili, I chose Kiswahili so as to share intimate experiences with participants as a leveller of power.

Apart from the particular issue of written consent, other fundamental ethical principles were adhered to. I was aware that before embarking on face-to-face interviews some participants would be worried about confidentiality issues. In this context, all participants were assured that what they said would remain confidential. Hence at the start of the interviews I would introduce myself and then inform the respective participant of the

purpose of the research. I would also give highlights about the storage of data just to show them that I would protect the integrity of their data as indicated in the information sheets given to all participants (see Appendix XII).

In practice my fieldwork notes and transcripts, as well as signed consent forms and other identifying material, were at all times kept in secure locked drawers. I also protected the audio recorder that was used in the interviews. Here I adopted a personalised password known only to myself. I also protected the recorder from unauthorised playback or duplication, as well as protecting my laptop by introducing a combination of identity username and password to gain access. The username and password were designed in such a way that they are not easily deducible.

To further emphasise confidentiality, each participant was asked to suggest a pseudonym that I could use in my thesis. While 30 participants suggested that I allocate a pseudonym, five preferred the use of their real names. Although I respected the preferences of those five participants, I could not grant their wish. This was because I was concerned that the interviews had addressed a number of sensitive issues, therefore the use of real names could jeopardise the anonymity of people and institutions that were mentioned in the interviews. For this reason I apologised and allocated all participants a pseudonym; thus the actual names of participants do not appear anywhere in the transcripts or thesis. But I also informed them, and it was agreed, that in some cases it might not be possible to totally anonymise the identity of the participant.

While a qualitative researcher like myself may wish to anonymise the identity of participants, the dilemma that arises, according to Corti (2008), is in the nature of a qualitative study like this one. Qualitative studies, by nature, often contain rich descriptive information about the participants. Such descriptive information may touch on the lives and other possible identifiable variables of the participants, such as age, gender, social class and so on. Corti and her colleagues (2008), who have written extensively on confidentiality and anonymity in research, warn us that in some cases it can be difficult to completely conceal the identity of participants without having to distort our data. My dilemma and challenge was therefore how to disguise the identity of some of my participants, particularly students with albinism, without introducing any distortion into my data. What I therefore did, in addition to using pseudonyms, was avoid mentioning

the names of the institutions that the students attended, as well as those of the specific programmes undertaken. Besides the challenge of concealing the identity of some of my participants, I was also challenged by researching in an environment where people have limited knowledge about their human rights.

As I was working in Tanzania, where research is less common and sometimes individuals have limited freedom to make their own decisions, as already mentioned I prepared information sheets to ensure the rights of participants. Here participants were informed about their rights to participate or not. They were also informed about their freedom to turn off the tape at any time or not to answer questions that they did not feel like responding to. Another thing that participants were informed of was their right to withdraw before or during the interview sessions, or to withdraw their data after the interviews. However, it was made explicit as to when they could withdraw. In this case participants could not withdraw their data after the end of February 2014, as by then I had progressed further with my data analysis. Up to the time of writing this thesis, no participant had withdrawn although I had frequent communication with some of the participants.

Another issue of ethical concern was the relationship between the participants and myself. Edwards and Ribbens (1998) in the book *Feminist Dilemmas in Qualitative Research*, highlight the importance of being sensitive to experiences we share with our research participants as well as the differences between us. I therefore approached the interviews being cautious about the balance of power between some students with albinism participants and myself. Here I thought about the age difference between us. Given the cultural norms in Tanzania, the dilemma was about building rapport with students some of whom were approximately 25 years younger than I was. This age difference was very likely to impact on the power balance in the research.

Again culturally, youths in Tanzania have less power than elders and this could also limit the formation of a good rapport between an older researcher like me and student youths. But in my case the relationship between the young participants and myself appeared to be good and strong. The students seemed to open up to me and spoke freely as they considered me to be like their mother. Although in other cultures this might seem an imbalance of power and would recommend the use of first names, in my experience and in some cultures such as the Tanzanian one, a mother is highly regarded as a best friend

and a person one can trust, look up to and confide in. The 14 students with albinism participants called me ‘mama’ which means ‘mother’ in English. They appeared to trust me and shared with me their painful and hopeful life experiences of having albinism as well as their navigation of HE opportunities.

Given the trust and hope that the 35 participants had confided in me I would have wished to involve them in critiquing their data at every stage of the research process up to the publication stage. But I found this arrangement to be expensive and time-consuming (Mason 2002). Instead, I promised the 14 students with the condition that after my thesis was examined and approved for circulation I would make a copy available to the Tanzania Albino Society and UTSS, NGOs in Tanzania which are responsible for the wellbeing of people with albinism. For other participants I promised that the thesis would be available online.

3.8 How I analysed my data

Braun and Clarke (2006), who are scholars in thematic analysis, consider thematic analysis to be flexible as it can be applied to any research, irrespective of the research’s theoretical and epistemological approach. According to these two scholars, thematic analysis has the potential to provide rich and detailed data. Given that my intention was to provide a rich and detailed analysis of the experiences of students with albinism in HE, I chose to use thematic analysis as a method to analyse my data. My data were 21 individual interviews and three focus group interviews. These data were also in the form of field notes, because I began the analysis in the field, my data analysis began when I was deciding what information to include and what not to include in my fieldwork diary, which I wrote up both before and after interviews.

Patton (1990) emphasises that field notes should be written promptly and comprehensively. He further suggests that our field notes should be descriptive, concrete and detailed because our observations and experiences during the research process are an important part of the data. Likewise, Alderson and Marrow advise us to keep notes on things like ‘who else was there, the atmosphere, the hints and suggestion of things that might not have been said and the reactions of others’ (2011: 112). In their view, such data helps researchers like myself to make a better analysis. Drawing upon Alderson and Marrow’s (2011) views, my

field notes included my observations and summaries of what the participants had said or things that had stood out. Most of the notes were written down soon after the interviews because during the interviews themselves I took limited notes because I felt it would not only affect rapport but also distract my attention, thus limiting my ability to listen to what the participants had to say.

Having finished the interview process, as I have mentioned above, I had to transcribe the interviews. Transcribing was the first step towards familiarising myself with my data (Riessman, 1993). Evers (2011) mentions four transcription formats, namely pragmatic, Jeffersonian, Goodwinian and Gisted transcripts. I drew upon the pragmatic format of transcription. According to Evers (2011), a researcher who draws upon a pragmatic transcription usually plans or designs her transcription according to her analysis needs, time and resources. In designing the pragmatic transcription, Evers (2011) says the researcher adopts a verbatim transcription and only includes aspects which she sees as interesting and relevant, leaving out things such as pauses, intonation, silences, hesitation and other non-verbal communications. I only included what I felt was relevant to my study. Similarly, I adopted a verbatim transcription and neither did I take into consideration pauses, intonation and so on. In this research I did not outsource the transcribing or translation of interviews due to limited funds.

In designing a verbatim transcription, I transcribed 21 individual interviews and three focus group interviews, and also translated nine individual interviews and one 119-page focus group interview. The overall transcription was 516 pages; thus the exercise was tedious and time-consuming, as well as emotionally and psychologically stressful. Of course before proceeding with my research I had clear guidelines on how to respond to the potential emotional or psychological distress that could occur to either the participants or myself as a researcher. But McCosker et al., (2001), Australian scholars, tell us that researchers and transcribers often downplay aspects of their own emotional and psychological experiences. I also placed more emphasis on ensuring the safety and security of participants and myself during the interview process, downplaying the possible emotional or psychological risks that could occur during the transcribing process.

Transcribing involved processing descriptions of disturbing, painful and distressing experiences and could therefore sometimes be difficult, even overwhelming. Sometimes

tears would drop from my eyes every time I remembered the agony that students with albinism and mothers of children with albinism often endure. These painful experiences occupied my thoughts so much that I began to be forgetful. In some cases, I could not even remember the titles of the books that I had been reading regularly. Also I developed a habit of crying for no apparent reason. I remember an embarrassing incident where I cried in my supervisor's office just because I could not remember the title of a book, which was in my handbag, and I was reading quite regularly. I then unconsciously began to isolate myself from friends and other doctoral colleagues because I did not want them to notice my sorrow or my red eyes. Such experiences show the affective load involved in researching pain and oppression.

These emotions were so intense that, as a novice researcher, it was difficult for me to judge what effect they had on the quality of the data analysis. But Kirkwood (1993), who had to attend counselling after experiencing emotional distress in her research, argues that those emotions played an important role in the quality of her research. Likewise, Letherby (2003) suggests that by analysing our emotional experiences we can add to our understanding of our participants' lives. In the same spirit Hobbs and May emphasise that 'feelings should be allowed back into accounts of research as a sign of strength rather than weakness, and as a means to combat false version of objectivity' (1993: xiii). They strongly argue that our feelings can have an enormous impact on our research and that we should therefore acknowledge them; if we were to ignore them, they might influence or mystify our final analysis. I share Hobbs and May's (1993) argument as well as that of Kirkwood (1993) and Letherby (2003). Given my own experience and the literatures, which as I have mentioned are mostly from the Global North, I am led to believe that emotions in research are not a cultural issue: they can travel across various cultures, including those in a country like Tanzania. In addition, I would say that my emotions also played an important role in this research because they enabled me to clearly understand and feel of mistreatment and pain that people with albinism often endure. Thus strengthening my final analysis.

Unlike Kirkwood (1993), I did not need any counselling because I recovered from the stress, but only after changing my transcribing modalities. I began transcribing only in the morning and limiting the time to four hours per day, and also alternated the transcribing of the data: I would transcribe the less painful interviews then switch to more distressing

ones and *vice versa*. I applied this strategy until I completed the transcribing exercise. What really motivated me to endure the painful experience and continue with my research journey, as already elaborated above, was my feminist commitment to change.

Having completed transcribing I decided to adopt a fully hands-on manual data analysis approach to analyse the transcripts. I did not opt to use any computer software, although I had attended two seminar sessions on NVivo, because I wanted to immerse myself within the transcripts so that I could easily identify salient themes and issues that were reflected upon by participants. Given that this is an exploratory study, manual data analysis allowed me to read and re-read the transcripts deriving from my data carefully, and several times. Here, I was familiarising myself with the data as well as searching for themes which helped me to create my data set. Braun and Clarke's (2006) term 'data set' refers to all the data that is being used for a particular analysis. Braun and Clarke (2006) suggest two ways of choosing our data: the first, from many or all individual items within our data; and the second, by identifying a particular analytic interest in data topics. In this case, according to Braun and Clarke, the data is 'all cases in which the topic is referred to' (2006: 6). In choosing my data, I followed the latter model. I was interested in how participants talked about the experiences of students with albinism in interacting with HE opportunities and so my data consisted of all reflections on themes related to the constraints and enablers in the lives of students with the condition.

After I established my data, I embarked on manual coding. Braun and Clarke (2006) point out that those undertaking manual coding have three options. The first, they say, is to code our data by writing notes on the transcripts. The second is to use highlighters or coloured pens to indicate potential patterns; and the last is to use 'post notes' to identify segments of data. Drawing upon Braun and Clarke's (2006) second scenario, I colour-coded the transcribed data of each participant basing on my broader overarching research question and my six sub-questions, which were sub-question two to seven.

After coding the data, I began searching for themes. As regards establishing themes, Braun and Clarke (2006) give us the options of using tables or mind-maps, or of writing the names of each code on a different piece of paper. I sorted and wrote different codes for latent themes, then organised them into appropriate data extracts. However, instead of using pieces of paper to write the names of each code, I opened a file on my computer

for each, which allowed the salient themes to emerge and be identified after reviewing and refining the coding. These themes, as already mentioned, were emotions, misogyny, and structure and agency. Each theme was then grouped together to identify sub-themes, then quotations from participants were selected to match each sub-theme and thereby interpreted in relation to my main theories, which I have mentioned in the introduction chapter.

Aware of the authorship privilege that is often accorded to researchers (Mauthner and Doucet, 1998), I chose to use quotations as a way of minimising such privileged power. Quotations were also another way of allowing the voices of participants to be represented in my thesis. Therefore, I attempted to include quotations from as many participants as possible, particularly those from students with albinism, but found that ‘some participants have more to say than others’ (Letherby, 2003: 118). In this way, the voices of some participants in this thesis, as a whole or in some chapters, appear more than others. However, I recognise the participation of participants in this thesis and respect all participants equally.

3.9 Summary

This chapter focused on how this study was carried out and the justification of the methods as well as the methodology that I adopted. It also discussed the dilemmas and contradictions that emerged in this research, and how they were overcome. As mentioned several times in this thesis, my research is about people with albinism, who are described by the UNHRC as people suffering ‘widespread discrimination, stigma and social exclusion’ (2013: 3). When involving such people in research, we are cautioned by Morris (1992) to be careful so that our participants do not experience similar mistreatment, or represent them in a way which tends to continue the discrimination and stigma they experience. While it is often the intention of social researchers to minimise possible mistreatment in research, feminist researchers often draw close attention to the possible exploitation of participants and the integrity of the representation of participants’ views and experiences (Watts, 2006). The feminist values and principles that I drew upon were meant, therefore, to minimise any possible hierarchies or exploitation. My research was thus underpinned by strict ethical concerns (Watts, 2006).

People with albinism are not only a marginalised group, but their voices have been silenced. As already pointed out in Chapter Two and elsewhere, few studies have given people with albinism an opportunity to tell their stories and lived experiences. I am aware that silenced voices are often eager to be heard and therefore should be allowed to do so, although feminists like Watts (2006) warn us that sometimes the chance to ‘tell it all’ can make participants vulnerable, as they might say more than they had intended. However, the features of feminist research require researchers to be good listeners (Hesse-Biber, 2006) and in accordance with these features, I listened attentively to my participants, thus giving opportunities to students with albinism, and even a mother of children with albinism, to ‘tell it all’ (Watts, 2006). Such opportunities were also made possible by the qualitative approach that I drew upon. Qualitative approaches, according to Mason (2006), provide our studies with rich and in-depth data collection and analysis. I was able to conduct an in-depth case study by means of 20 face-to face semi-structured interviews, one Skype interview and three focus group discussions, providing a better understanding of the real lives, struggles and experiences of students with albinism in interacting with HE opportunities.

Case studies like this one are not free from criticism. For example, scholars such as Miles (1979) and Daft and Lewin (1990) are concerned about the rigour of case study research, whereas Yin (1981; 1994) questions the possibility of generalisation from case study findings. Yin’s (1981; 1994) argument here is that with case studies, we often study a phenomenon in its contexts and not beyond that. However, Flyvbjerg (2006) believes that case studies can be generalisable. In his view, a case can be an expert or a knower of a particular knowledge or experience. That very expert or knower can therefore be a basis of knowledge in several other similar cases concerning that particular knowledge or experience. In my study, I regard students with albinism as experts or knowers of living with albinism and their experiences of interacting with HE opportunities. I believe their expertise or knowledge can work as a basis for understanding the experiences of other students with albinism in HE. To this end, I have provided room for the reader of this thesis to read the experiences of students with albinism from multiple sources so that she can make her own judgement in terms of albinism in HE.

The following chapter is the first chapter of the three analysis chapters. It analyses emotional factors that influence the experiences of students with albinism in their interaction with HE opportunities.

Chapter Four

Emotions of Hate, Fear, and Ambivalence: Contradictory Perceptions of People with Albinism

4.1 Introduction

Various scholars theorise emotions differently. Sara Ahmed (2004a) sees emotions as being widely influenced by social or cultural practices rather than by psychological dispositions. She argues that emotions do not reside in the subject but circulate towards individuals or objects (Ahmed, 2004: 117). In this way, Ahmed, (2004a) like anthropologists and sociologists (Hochschild, 1983; Rosaldo, 1984; Lutz and Abu-Lughod, 1990; White, 1993), extends emotions from an individual psychological state to social relations. Ahmed's (2000; 2004a) main argument is that emotions are experienced through social relations and/or cultural practices. Here she sees emotions as performative, suggesting that they can perform multiple social roles such as joining some groups together and in so doing exclude, stigmatise and marginalise others. In Ahmed's (2004a) view emotions can shape individuals and also structure how people relate with each other, thus securing social hierarchies and differences as they circulate. Ahmed regards them as collective or public phenomena, rather than private, or belonging to an individual.

Emotions are various, but this particular chapter focuses on hate, fear and ambivalence. Such a focus allows this chapter to analyse emotions within social and cultural practices, and attempt to explore how emotions can work to categorise albinism as different and thus affecting the life experiences of those with the condition. I underpin my analysis with Sara Ahmed's (2004a) notion of affective economies and fear of difference as well as Pierre Bourdieu's (1984) concept of symbolic violence.

In her notion of affective economies Ahmed sees emotions as doing things, as they can align individuals with communities – or bodily space with social space- through the very intensity of their attachments (2004a: 119). Here she does not only refer to emotions people often feel, but also to the emotions that they elicit. Thus suggesting how various emotions can circulate and stick around albinism and work to exclude, stigmatise and marginalise them, consequently affecting their life chances including education opportunities. This

way, emotions can produce unnoticed or unconscious domination, which Bourdieu (2001) refers to as symbolic violence.

Bourdieu (2001), in his book *Masculine Domination* (translated by Nice, 2001), talks about unspoken and unconscious dominations which often occur within everyday social life, and which he calls symbolic violence. For Bourdieu, symbolic violence is ‘the imposition of systems of symbolism and meaning upon groups or classes in such a way that they are experienced as legitimate’ (2001: 512). By this means, dominant groups often impose their views, culture and way of being and make these a legitimate way of being human. In this research, those without albinism in Tanzania are doing precisely this. For Bourdieu (1984; 2001), such dominance is symbolic violence as it is a power relation or mechanism of power over others. Symbolic violence, in his view, is not a physical violence and neither does it cause bodily or physical violence; rather, it causes psychological or emotional harm. Thus Bourdieu’s (2001; 1984) notion of symbolic violence provides this research with the basis for establishing unnoticed or unconscious domination produced through emotions on the everyday life experiences of students with albinism that widely affect their interaction with HE opportunities.

Emotions are universal phenomena, but they are widely affected by culture (Ahmed 2004). This makes the analysis of cultural structures such as myths and beliefs essential for the understanding of emotions and forms of symbolic violence that circulate around albinism. Holland and Ramazanoglu (2002) refer to myths as traditional stories that address various ways of living and being. Although the myths that Holland and Ramazanoglu (2002) define are in relation to women, they can also apply to albinism. In this context, I would say that there is a vast number of traditional stories about albinism. Given that those without albinism widely hold the power of domination, they often use that power to construct various myths about albinism. They relate albinism to bad omens, curses and ghosts, or claim it is a result of the mother’s adulterous relations (see also section 1.7). Conversely, it has been regarded as a source of wealth and prosperity (Tanner, 2010; UNHRC, 2013). These myths have circulated and aroused emotions of hate, fear or ambivalence. As mentioned above, emotions can create boundaries between people, joining some while separating others. In the case of this study, emotions have separated people with albinism from those without albinism and thus people with albinism have been set apart as different, and a collective or hegemony of those without albinism has

been established. The collective or hegemony gives power to people without albinism to subordinate people with albinism and those without albinism circulate emotions of hate, fear or ambivalence (Ahmed, 2004), which can be a cause of what Bourdieu (2001) refers to as symbolic violence exerted in order to maintain their hegemony. In this case, the power relation between those with albinism and those without often works to ensure that the latter dominates the former. For this reason, myths and beliefs are contested terrains where people without albinism compete for hegemony over people with albinism.

Frameworks of power relations within albinism are various and some are contradictory and suggest irrational myths. On one hand, the myths delineate hatred and fear towards albinism by constructing the condition as a curse, a bad omen or a disaster; on the other, albinism is considered a source of success and prosperity (Tanner, 2010). It is obvious that people often hate and fear curses, bad omens or disasters but that they love success, wealth and prosperity. Relating albinism with negative and positive objects could mean that albinism is hated, feared, and loved at the same time. These signs of affect form the surface of a group of those without albinism which hates, fears and loves a group of people with albinism.

The irrational myths and beliefs about albinism which I mention above can, to a large extent, incite hatred and are therefore instrumental in the bullying, traumatising and harassment of people with albinism, particularly children. We are informed (Lund, 2001; Baker et al., 2010; UTSS, 2013; UNHRC, 2013) that children with albinism are often bullied, traumatised, harassed and negatively labelled not only by some of their fellow students but also by some of their teachers. Several studies suggest that students may drop out or minimise their school attendance to avoid bullying or harassment (Peterson and Rigby, 1999; Rothon et al., 2010). Lynch and Lund (2011) found in their study of the education of children and young people with albinism in Malawi that some children with albinism were not going to school because some students were laughing at them. Some students with albinism therefore had an irregular school attendance or had to drop out of school altogether because myths and beliefs which circulate on albinism prompted bullying and harassment in schools. Emotions can therefore do things (Ahmed, 2004), in this case limiting school attendance or causing students to drop out.

In this study, Loveness, a female student with albinism, talks about how she almost left school because of bullying and harassment. It was only after her brother repeated a year so as to be in her class and defend her against bullying that she was able to continue with school and consequently progress to HE. Similarly, Lucas, a male graduate with albinism, reflects upon how he dropped out of school for three months and took up private classes because of the negative treatment he was receiving from his teachers. Likewise, Isaack dropped out of school for one year because of harsh treatment from both students and teachers. All this means that frequent bullying and harassment, which are widely instigated by myths and beliefs, have affected the smooth academic progress of students with albinism, and thus their inclusion in all phases of education, including HE. This means that emotions which surround albinism are among the barriers limiting the participation of students with albinism in HE. Thus making the number of students with albinism in HE to remain negligible, despite widening participation policies in Tanzania and an increase of 190.2 per cent in the HE participation rate from the year 2005 to 2010 (Mwaipopo et al., 2011).

The provision of education, including HE, can in some cases be influenced by the culture of a particular society (Chataika, 2007), including its myths and beliefs. These influences can affect the participation of groups seen as different. Showing cultural implications, a study by Morley et al (2010) reveals that in Tanzania, female applicants were more likely to be denied admission into university than male even when the women had the required qualifications. This could also be the case with people with albinism. Peter, a male graduate with albinism with a low social economic status talks in this study about how he entered university by chance. Peter reflects on how he applied twice for university admission but on both occasions was not selected although he met the entry requirements. Ester and two NGO officials, Abraham and Philemon, also talk about Peter's admission denial. Ester, Abraham and Philemon, who were interviewed separately, and Peter himself, point to albinism as a reason for the denied access and to a myth that links albinism with limited cognitive capacity. Brandt (2011) and Beauchamp-Pryor (2012) suggest that some HE institutions misrecognise the ability of disabled students and can thus block their admission. The existence of such ideologies in Tanzanian universities is likely to block the admissions of disabled students, including students like Peter.

In some instances, myths that people with albinism have limited cognitive capacity make parents refrain from taking their children with albinism to school, believing that it is a waste of resources, as the child could not adequately participate in education (Odula, 2009). Likewise, some teachers who believe in such myths make no efforts to assist students with albinism with their learning processes (Luande, 2009). The impacts of such myths are explained by Happiness when she says:

(w)hen I was in standard seven when I would do classroom examinations, I would fail therefore I was always taken as somebody who doesn't know anything. Teachers would say she doesn't know anything. But when it came to mock examinations, which were printed teachers would be surprised with my good performance. They used to say it is not possible, so they started calling me a witch. (Happiness, female graduate with albinism -LSES)

While the myth blames those with albinism for possible poor performance, it overlooks the limitation of learning and teaching facilities that the education system often provides for students with albinism who, as already mentioned above, often suffer from poor vision. Here, as Bourdieu (1984) suggests exclusion works as self-exclusion. Thus suggesting traces of symbolic violence towards students with albinism like Happiness who are often perceived by teachers as incompetent students and witches when they perform well. Thus providing limited assistances towards their learning. The lack of teachers' support for students with albinism sometimes influences parents to also believe that their children with albinism have limited learning ability, resulting in parents' believing that educating children with albinism is a poor investment and thereby justifying their decision not to invest in their children's education and legitimising the misrecognition of their cognitive ability.

The myth that links albinism with limited cognitive capacity is a sign of hate. Hate is often tied with fear because in most cases 'others are often brought into the sphere of my or our existence as a threat' (Ahmed, 2004: 51). In this case, the hate that circulates around albinism due to the myth of limited cognitive capacity could be prompted by the fear of poverty that some parents of children with albinism imagine they risk if they enrol their child in school. Enrolling children in school often means committing financial resources. When these are limited, providing for the schooling of a child with albinism can be a threat and a huge risk. This is even worse for a girl child with albinism, because 'male disabled children, in general are privileged over girls because there is an expectation that

they can become breadwinners (Rousso, 2003 cited in Mumba 2009: 256). What Rousso cited by Mumba (2009) talks about is hate towards a girl child because she is considered as a passive human being who is unlikely to be economically supportive to the family. This emotional hate of a girl child can incite:

(b)eliefs that women with albinism are either free from HIV/AIDS or can cure HIV/AIDS which has sometimes led to rapes and subsequent HIV infection to women with albinism (Philemon, male non-governmental (NGO) official).

Myths therefore do not only incite symbolic violence but also physical violence as reflected upon by Philemon. This kind of violence threatens the safety of women with albinism in public space like schools and universities. Thus resulting in the absence of women with albinism in public spaces due to fear.

Myths that circulate emotions on albinism as I have indicated above are vast. However, I focus my analysis on three emotions that had emerged from my data. These emotions are hate and fear as well as ambivalence. To a large extent, emotions of hate and fear are interrelated. This connection was found to influence feeling such as pain, shame and disgusts that widely surrounds albinism. This way, in this chapter I have also analysed these feelings and their effect on people with albinism lived experiences including the academic experiences of the 14 students with albinism.

4.2 The fear that sticks on albinism

Ahmed (2004a) agrees with Rachman's (1998) description of fear as an emotional reaction to an identifiable threat. Albinism is widely feared as it is often identified as a possible life threat. Ester a female non-governmental official, for example, says:

(i)f someone has a baby with albinism the whole society thinks it will be cursed. [So] if there were droughts they would blame them on the person with albinism in the society. Floods or any natural disaster [they would say] it has happened because there was or there is a person with albinism. (Ester, female NGO official).

Fear, according to Ahmed (2004a), makes people link other people with fearsome objects. Curses and natural disasters are objects that are often feared by humans. Associating albinism with curses and natural disasters makes people with albinism the cause of fear. Natural disasters are sometimes difficult to contain, even in technologically advanced countries like the US, the UK and Japan. We have, for example, witnessed how these

countries have failed to contain floods or earthquakes despite their advanced technologies. Such outcomes make natural disasters something which is not only feared in less advanced countries like Tanzania, but worldwide. Therefore, associating albinism with objects of fear can exclude those with the condition from public spaces because:

(n)obody wants to touch them because the myths tell people that if you touch a person with albinism you would be infected with the condition, they call it an illness or a disease. (Ester, female NGO official).

The fear of death could have generated such a mythology (Ahmed, 2004). Humans often fear death, so the myths that associate albinism with deadly illnesses and diseases could to a large extent induce fear. Thus make people read the condition as fearsome or fearful. In her book *Stranger Encounters: Embodied Others in Post Coloniality*, Ahmed (2000) explores how people are constructed as different or strangers. According to Ahmed (2000) peoples' differences are constituted through encounters. Such encounters she says are unequal because histories of encounters had already marked some people as strangers or different. This way, nobody wants to touch people with albinism because histories transmitted through myths label them as fearsome.

When Peter, talks about his life experiences of interacting with HE opportunities, he reflects upon how he was seen as fearsome, explaining how students in his class and people generally have often hesitated to shake his hand or sit next to him in the classroom or in the bus. His proximity poses fear (Ahmed, 2004). The fear that Peter implies is not only elicited among students in his school, but also by some adults in his community, showing not only that excessive fear sticks to albinism but also that emotions are not private but, rather, socially-organised issues (Ahmed, 2004). Fear of albinism circulates in society and thus influences not only individuals but rather the society as a whole. In this case, fear has worked to align and demarcate Peter as a stranger. Peter and others with albinism are thus shunned, and seen as people who do not belong in public spaces.

Peter is not the only participant with albinism who experienced a sense of not belonging in school. Meshack, another male graduate with albinism, also reflects on how he was removed from a faith-based school after he was found to have albinism. He passed an examination for entry into the faith-based school and was therefore selected for entry but, upon reporting to the school, was told by the head teacher:

(s)o, gentleman, unfortunately you will have to leave and go home and ask your parents to find you another school (Meshack, male graduate with albinism- LSES).

Ahmed (2000) emphasises that a stranger is a person who we have already recognised rather than the person we fail to recognise. This means that the head teacher had already recognised and demarcated people with albinism as outsiders and therefore Meshack was marked as a person who does not belong in that school. Gold and Evans (1998) in their book *Reflecting on School Management*, inform us that the philosophies and values of head teachers often guide the management styles and practices of schools. They say that these styles and practices enable head teachers to intercede against possible external influences which might counter the agreed norms and values of their schools. In light of this view, I would say that the ideas and beliefs about albinism held by Meshack's head teacher could be what informed the school's admission policies and decisions; that even when Meshack had passed the examination necessary to enter the school, this was the factor which caused his exclusion. The fact that Meshack passed the examination could not mediate the admission policies and decisions of the school with regard to not admitting students with albinism like Meshack.

While being seen as a stranger could be a reason for Meshack's refusal for admission, emotions of fear could be another reason for his refusal. Metcalf (2003 cited in Baker et al., 2010: 175), for example, talks about how a pregnant teacher at a primary school in Zimbabwe placed a nine-year-old student with albinism at the back of the classroom because she feared that coming into close contact with the student would result in her giving birth to a child with albinism. According to Metcalf (2003), placing the student with poor vision at the back of the class affected the child's learning and consequently her academic performance. In this case, I would say that emotions not only work to deny the right of inclusion in education but also affect the learning and academic performance of students with albinism, thus impacting their interaction with HE opportunities.

Simon, a male student with albinism with LSES also shares his school experiences. Simon reflects on his primary school experiences and recalls that:

(i)t annoyed and hurt me but I could not do anything about it, because students in my primary school would refuse to share textbooks with me. They would even refuse to touch a textbook that I had touched because they would say that they would be infected with my fatal disease. (Simon, male student with albinism -LSES).

Through myths, students have been made to believe that albinism is dangerous. These beliefs circulated within Simon's school bring fear of survival to some students. Fear then works to construct Simon as a 'stranger' among his fellow students, thus implying what Ahmed (2000) refers to as 'stranger danger'. In Ahmed's terms a 'stranger danger' transgresses perceived boundaries and engenders fear in the native (2000: 37). This means Simon engenders fear to students without albinism in the respective school. It therefore followed that students without albinism were aligned as bodies at 'home', having domination or monopolized power over the textbooks and other resources. From such domination Simon's right of sharing a textbook was denied. Likewise, his right of access to resources and to participate with other students was equally denied.

In Tanzania it is a common practice for students, especially those in primary and secondary schools, to share textbooks during classes, as a consequence of reduced resources. One textbook may be shared among four to five students. So when Simon was denied such opportunities, his learning process was to a large extent affected as lack of textbooks might have affected his academic achievement. Textbooks, as Hutchinson and Torres suggest, are important tools for the students' learning process as they supplement what a student learns in class (1994: 327). Textbooks, therefore, are still a highly important learning tool, particularly to students in countries like Tanzania where online reading materials are often not easily accessible. Bourdieu and Boltanski (1981) suggest that educational achievement is widely linked with participation in cultural actions such as book-reading and accessibility. Given the Tanzanian context, limiting Simon's access to textbooks would considerably affect his educational achievement.

Poor vision limits the ability of students with albinism to read books in small font, or at a distance. This means they need special textbooks which have large print. Such textbooks would support their reading, thus allowing them a comfortable reading and learning environment. The 14 students with the condition I interviewed talk about the lack of large-print textbooks in all phases of their education, raising the need to have appropriate learning facilities such as magnifiers or monoculers so as to support their learning.

Going back to how Peter, Meshack and Simon were seen as strangers or outsiders, Grace and Happiness reflect a different pattern. For them, there was a sense of belonging. Grace talks about how she received widespread support and closeness from people in

her community, including her fellow students, teachers and neighbours. Like Grace, Happiness talks about the support and encouragement that she often received from people in her village, as well as from students in both her primary and secondary schools. To a large extent, Happiness a female graduate with albinism attributes her participation in HE to some of her neighbours and community members in her village. She recalls how some of them used to see her as an academically capable student and would therefore encourage her to work hard at her studies. Here, as explained in detail in Chapter Six, Happiness talks about the discussions she had with her fellow students, largely attributing her participation in HE to the respect and acceptance accorded to her by fellow students and community members. The cases of Grace and Happiness are an indication that albinism is not always seen as out of place or excluded in institutional settings like schools. There are times when those with the condition are included.

Grace and Happiness are from the same region in Tanzania. Their region has no known incidences of people with albinism killings or amputation. Moreover, Grace and Happiness were the only participants with albinism who talk about their communities providing them with sunscreen lotion. Grace, for example, started using the sunscreen lotion at the age of four, while Happiness was five when she began using it. They both attend skin clinics every six months before they are issued with the lotions. Both Grace and Happiness have visibly smooth skin with minimal sunburn.

Going back to the experiences of exclusion, other participants with albinism who share similar experiences of not belonging or in other words being seen as fearsome are Sarah and Angel. Sarah and Angel are both female students with albinism with LSES. In separate interviews, Sarah and Angel, who were both in boarding schools, talk about their experiences of being excluded by their fellow students. Sarah and Angel reflect on incidents where their schoolmates would isolate and avoid touching things that they had touched. While both Sarah and Angel show signs of sorrow when discussing their educational experiences, Angel goes further and says:

(s)ome students would hold the spoon like this (indicating the holding) and then they would wash it as if I was dirt or rubbish. It is very painful when your fellow students treat you as dirty or disgusting. (Angel, female student with albinism- LSES).

Ahmed (2004a) would argue that the act of students refusing to touch a spoon that Angel had touched implies that albinism has already been seen as dirt, and Angel as a carrier of

dirt. To avoid that contamination, therefore, students in Angel's school attempt to distance themselves from that dirt. In addition, Angel implies Ahmed's (2004a) sticky notion, in which Ahmed suggests that an object can assume a value of disgust when it is repetitively named so. This could mean that through repetitive myths and beliefs albinism had assumed a sticky value of disgust. It seems that the sticky value of disgust for albinism has leapt from epoch to epoch, influencing some students in Angel's school to equate albinism with disgust. This repetition and generational transmission of disgust prevents the condition from acquiring new meaning and values even now. The circulation of disgust produces a system of oppression of those with albinism like Angel. Oppression, according to (Rich, 1976; Carlson, 1986 cited in Morley, 1992) causes a long-lasting hurt, which often affects our wellbeing and thus our various social and economic opportunities. In this way, the various opportunities of Angel and other people with albinism, including those of interacting with HE are likely to be affected by the disgust that is attached to albinism.

Sarah is another female student with albinism who talks about her experiences of being found 'disgusting', this time within HE. Sarah's reflection is an indication that disgust towards albinism was not only circulating in schools but also in HE, emphasising the stickiness of disgust towards albinism at all phases of the Tanzanian education system. Here Sarah talks about her experiences in HE, and says:

(w)hen I would try to befriend some students in my course programme, they would indicate that they don't want you because they are not willing. Like as if I am disgusting, but what can you do. I would just be with them just like that. (Sarah, female student with albinism- LSES)

Sarah illustrates how disgust worked to construct her as 'out of place'. Such sticky emotions, according to Ahmed (2012), can make some students in universities remain as guests even though institutions may be implementing diversity policies. This means that institutions, including Sarah's university, often have people who are considered as norms. Any person seen to be different from this norm is therefore considered deviant or outsider. I can say that Sarah and other students with albinism have remained outsiders at their universities even though they have been physically present there because albinism is not the norm in universities. In other words, I would say that despite Sarah's being a university student, she is to some extent not fully included, as she is a guest who does not belong there. By being a guest in HE, means that Sarah is excluded.

By feeling the exclusion Sarah reflects upon her struggle to be included. To Sarah her inclusion often depended on the empathy of students to accept interacting with her. This power relation still privileges students without albinism and thus subordinates those with albinism, showing traces of symbolic violence in Sarah's and others like Peter, Meshack, Simon, Angel and Happiness' processes of interacting with other students in HE.

As I have said above, Ahmed (2012), in her book *On Being Included: Racism and Diversity in Institutional Life*, maintains that some HE institutions have assumed certain people as their norm. This being the case, Sarah's university has norm bodies and Sarah's body is not one of them. Being outside the norm, Sarah is categorised as different and therefore avoided. According to Ahmed (2012), when norm bodies are in place they construct deviant bodies, which assume a vulnerable position. The position of vulnerability that Sarah assumes can affect her studies, as she may at times feel a discomfort or incompetency, particularly when required to participate in learning activities such as group discussions or assignments. Thomas provides a similar example of being shunned by other students, recalling how he felt worthless when he was removed from his discussion group after one student advised group members to do so because his presence would make the others fail their university examinations. According to Thomas, that sense of worthlessness affected his participation in class discussions as well as in other group discussions.

Another participant who reflects upon the stickiness of disgust towards albinism is Abraham a male NGO official who has albinism. Abraham recalls incidents where some people would spit down when they came face-to-face with him. In Tanzanian culture people are likely to spit when they see or smell something disgusting or unpleasant. This could mean that a thing that looks or smells disgusting or unpleasant is hated and pushed out through spitting. Spitting can be triggered by emotions of hating what is disgusting. This way, spitting in relation to albinism could mean pushing out what is hated, making spitting an act of symbolic violence. Spitting, then, works as violence meant to symbolically harass and abuse those with albinism who in Ahmed's (2004a) words are seen as disgusting. As far as I can remember, spitting out albinism has been practised for so many years that it now seems as if it has been culturally legitimised, has become habitual and is not taken as an act of violence. This is because we often believe that violence is only harmful if it is physical (Bourdieu, 1984).

Angel is another participant who talks about her life experiences of being spat on. Given the age difference between Angel and Abraham as shown in Table 1 and 5, there is an indication that ‘spitting out’ albinism has leapt between generations and is still practised. This means that affect has stuck to albinism and has slid from one people with albinism to the other. In her article *Affective Economies*, Ahmed suggests that ‘the movement between signs does not have its origin in the psyche, but is a trace of how histories remain alive in the present’ (2004a: 126). In this case, I can say that in relation to spitting out albinism, history is basically responsible for the circulation of disgust which has circulated around albinism for years and which continues to circulate in the present.

While disgust continues to circulate on albinism, emotional act of spitting was not only a practice in Tanzania but was also practised in some other African countries. For example, in Zimbabwe and Malawi we are told people also spit down when they meet people with albinism (McNeil, 1997; Baker et al., 2010). In this particular research, Angel, who is approximately 25 years younger than Abraham, recalls spitting incidents and says:

(s)tudents in my school and other people would spit down when they see me and would call me zero zero [ghost] instead of calling me my name. (Angel, female students with albinism- LSES).

Given Angel’s reflection, the meaning of spitting seems to shift from pushing out disgust to pushing the fearsome ‘ghost’ out of the spitter. This way, spitting could also symbolically be an assurance of safety and give a sense of security to those who feel and read albinism as a threat to their lives. This could mean that in Tanzania spitting is contradictory, as it could either mean pushing out disgust or pushing out a fearsome object. Both meanings, however, suggest that the disgust and fearsomeness felt towards albinism are pushed out, so that they do not enter the spitter.

Eliza who is the mother of children with albinism also confirms the spitting out of albinism. Here Eliza talks about the incident where she was walking with one of her children and met a pregnant woman she says:

(t)here was a time I was with my kid we were walking and I saw a pregnant woman when she saw us, she looked at my son you know what she did she just took her piece of *khang* and spat on it and crossed the road so that we don’t meet face to face when I asked some people why the woman acted so they said it was because

she was afraid that seeing a person with albinism when she is pregnant she might give birth to a child with albinism. (Eliza, mother of children with albinism).

When talking about disgust, Ahmed (2004a) says that in order for a person to be disgusted the object must have got too close: that it is through a sense of proximity that an object is felt to be disgusting or sickening. Going by Ahmed's notion, I would say it was only when the pregnant woman met Eliza and her children that she felt the disgust and spat, and therefore had to cross the road so as to distance herself from the disgust. I can also say that the interaction between Eliza's child and the pregnant woman is what sickened the woman and caused the unpleasant feeling which made her spit on a piece of *khanga*. *Khanga* is a colourful wrapping cloth often worn by women especially those in coastal regions of Tanzania.

Going back to my discussion about spitting, spitting is not only practised in Tanzania. Other cultures spit on the ground for various reasons. In China and Turkey, for example, people spit as a way of protecting the inside body. To the Chinese and Turkish, spitting is often to get rid of evil, destructive influences or diseases from inside the body (De Castella, 2011). This could refer to the expulsion or exorcism of evil or diseases. This view is similar to that in Tanzania, although contrary to that of some countries of the Global North. In the UK, for example, spitting is seen as ugly, anti-social and a potential for spreading diseases (De Castella, 2011). Likewise, in the United States of America (USA) spitting is interpreted as a spread of disease (Mestel, 2000). In 1900 some states in America recommended restricting and regulating spitting as a way of controlling the spread of diseases (Mestel, 2000). While spitting in the Tanzanian context could suggest that emotions were outside the spitter and created by the object of disgust, the views in the UK and USA suggest that emotions are *inside* the spitter and should be prevented from entering society. This difference could mean that emotions are cultural phenomena and can sometimes be experienced and perceived differently by different cultures. Despite these differences, some cross-cultural connection between spitting and the emotions of hate and disgust on albinism in the Tanzanian context is clear.

Hate and disgust can to a large extent circulate around what is labelled strange or alien, or what Ahmed (2004a) refers to as that which is threatening to violate pure bodies. The violators of pure bodies, according to Ahmed, are likely to involve emotion of hate or pain

because purity is reliant upon a repeatedly imagined intrusion (2004a: 119). Albinism, as indicated in the preceding chapters, is widely read as a violator of the norm. This view differentiates those with albinism from the rest of the population as already mentioned are visualized as not the norm. This differentiation in some cases projects pain onto albinism so:

(s)ome parents murder their children with albinism at birth so that even the next-door neighbour will not know that there was a child born with albinism in that house. (Ester, female NGO official).

Some myths see parents of children with albinism, particularly mothers, as having been involved in witchcraft, or cursed or punished by God (Baker et al, 2010). Also traditionally in some African countries it was sometimes considered a taboo to give birth to children with albinism (Mesaki, 2008). Such traditional beliefs can cause painful experiences for some parents especially those believing in traditional religions. Ahmed (2004a) suggests that previous experiences and how well we remember those experiences is what determines the amount and quality of pain that we feel. So the amount and quality of pain that parents of children with albinism experience and remember could shape the relationship of parents and their children with albinism. Emotions, according to Ahmed (2004a), can help to form relationships between individuals. They can, as mentioned above connect individuals with some people while distancing them with others. As it was a painful experience for some parents to give birth to children with albinism they might have been distancing themselves from their children through infanticide. The loss of children with albinism, as Butler puts it 'are not seen pertinent' (2004a: 32). This way, these parents read albinism as a cause of their pain, particularly mothers who are often accused or blamed for having children with the condition, as discussed in detail in Chapter Five.

Ahmed (2004a) says objects can sometimes be read as a cause of a certain emotion. A study carried out by South African scholars Kromberg et al. (1987), on the response of black mothers to the birth of an infant with albinism reveals that some mothers of children with albinism took about nine months to accept their children fully. The study also reveals that some mothers often kept a distance and talked to their children with albinism less. It is possible that these mothers in the South African study could have read albinism as a cause of their pain, therefore felt they should distance themselves from it. Eliza, a mother

of children with albinism, as explained in detail in Chapter Five talks about the pain that she experienced in bringing up children with albinism. In this way:

(s)ome of the students with albinism are not accepted at home. [So], some are raised by foster parents, some in missions or in religious institutions by religious people or some are also raised by extended families in that aspect. (Elizabeth, female teaching staff).

As human we often avoid anything that would cause us physical or emotional pain. In terms of physical we avoid knives, blades or fire that can burn us and cause painful bruises. In terms of emotional we often attempt to avoid listening to information or news that can hurt us. It is common, for example, to deny any information such as deaths, illnesses or accidents of our loved ones or our own illnesses. There is also tendency, for example, television channels or film producers to warn viewers about incidences in the transmission that can cause pain. By such warning it is expected that some people will decide to watch the transmissions while others will decide not to. Similarly myths and beliefs work as warnings about the pain that surrounds albinism. Thus some parents will decide to believe such myths and some will not.

According to Ahmed (2004b), pain often involves an action of rejection. This means some parents who attach albinism to pain can reject their children with albinism. While Ahmed (2004b) says pain influences an act of rejection, she also informs us that it can slide into other feelings such as sadness, fear, grief, shame, despair or even anger. In relation to feelings of shame, according to Ahmed (2004b) when a person is shamed she or he could turn to self-negation. In this way, some parents of children with albinism can be in denial and feel like failures for producing what is read as not a norm. Then this very emotion of shame can also work to register albinism as shame. As such, albinism is a stigmatised or spoiled identity. Goffman in his book *Stigma: Notes on the management of spoiled identity*, refers to stigmatised or spoiled identities as people who possess characteristics, which had been deeply discredited (1963: 3). This means that the social identities of students with albinism had been spoiled because they are connected to objects that are not acceptable in the society such as disgust, low cognitive capacity, immorality and so on. Therefore, the spoiled identity that circulates towards albinism connects with shame. This has made some parents of children with albinism, particularly fathers, feel shame and thus reject their children with albinism. For example, Ester, Abraham and Philemon, who are

NGO officials, talk about how they have received a number of cases of women who were left by their husbands or partners for giving birth to children with albinism.

Likewise, four participants with albinism, namely Sarah, Happiness, David, and Angel, also talk about being rejected by their fathers at birth. Even those who were not rejected by their fathers at birth, like Isaack and Peter, both male graduates with albinism with LSES, and Thomas, a student with albinism with LSES, talk about being neglected and hated by their fathers, indicating patriarchal shame for having produced what is seen as an inferior being. In emphasising that his father treated him harshly, Isaack recalls how his mother would ask his father why he was treating him differently from his siblings.

While the data of this research largely indicate that some fathers were treating their children with albinism harshly, Grace, Lucas and John stand out among the 11 participants with albinism in this research, because they were loved and respected by their fathers. Grace, Lucas and John are not the only participants who indicate paternal love and respect for albinism; Eliza, a mother of children with albinism, also talks about how her husband fully accepted and supported her children. The reflections of Grace, Lucas, John and Eliza critique the notion about shame experienced by the father that circulates around albinism. However, the data from the seven participants mentioned above were not the only ones to reflect upon patriarchal shame circulating around albinism; some literatures in Tanzania and in other countries in Africa indicate the same. For example, Baker et al. (2010) show evidence of patriarchal shame on albinism, which was documented by Livingstone (1887) in the nineteenth Century. Baker et al. in their article *The Myths Surrounding people with albinism in South Africa and Zimbabwe* quote Livingstone stating that:

(d)uring the time I resided in Mabotsa, a woman came to the station with a fine boy, an albino. The father had ordered her to throw him away, but she cling to her offspring for many years. After I left the place, the mother is said to have become tired of living apart from the father, who refused to have her while she retained the son, she took him out one day, and killed him close to the village of Mabotsa, and nothing was done to her by the authorities (Livingstone, 1887: p.576 cited by Baker et al., 2010: 172-173).

The existence of patriarchal shame circulating on albinism is also confirmed by a Tanzanian sociologist, Simeon Mesaki who quotes an incident of a person with albinism in Mali who was rejected by his father at birth after his father had said ‘what is this thing?

A black man with a white skin’? (Mesaki, 2008: 5). In addition, the UNHRC quotes a girl with albinism who says:

(I) still remember my difficult childhood my father has always rejected me because I have albinism. One day he told my brother that I represented the devil, that I was not his daughter. He refused to send me to school (2013: 13).

Such emotional reactions show that being different can sometimes become a reason for other peoples’ shame (Ahmed, 2005). Shame therefore works to constrain students with albinism’s participation in schools and consequently HE. Thus answering my second sub-section what are the barriers and enablers to their participation in HE? For example, Thomas, reflects on his education experiences and says:

(m)y father did not care much about my education. He didn’t consider it important for me. He considered me as someone with limited cognitive capacity who should stay at home. But his emphasis and concentration were on educating my siblings who are not disabled (Thomas, male student with albinism- LSES).

Given the superiority norm of masculinity that often requires men in Tanzania to avoid displaying weakness, shame can be one of the reasons that Thomas’ father attempted to confine Thomas to the private space of a home rather than allowing him into the public space of a school where his albinism could easily be seen. In other words, Thomas’ father might not have wished Thomas to be exposed to the public, because his exposure could compromise his masculinity as a father. Ahmed suggests ‘the bind of shame is that it is intensified by being seen by others as shame’ (Ahmed, 2005: 75). In this context, Thomas’ father could have assumed that his shame would be intensified when the public learnt that he had given birth to what is read as shame. Intensified shame, according to Ahmed (2004b), can sometimes be injurious and thus be converted into a construction of boundaries. The boundaries that Ahmed (2004b) talks about are likely to affect the good relationship between parents and children with albinism or between people without albinism and those with albinism.

4.3 Enacted boundaries against albinism

As indicated in the previous section emotions often work to enact boundaries between people. Such boundaries bring people together while separating others. In case of albinism the boundaries are between the collective of people without albinism and that of a collective of people with albinism. Through such a collectivity the struggle has been

to defend the boundaries of the collective of people without albinism who are a group holding the power of being the majority. Involved in such a struggle Isaack, reflects on his-experiences and says:

(w)hen in my Form one the first day I reported to school, you know I am tall so this short guy removed me from the desk and that was the only empty desk as the class was overcrowded but he removed me and told me that he had never seen a person with albinism in secondary school. He even told me he had never seen anyone with albinism studying and asked me if I have ever seen a person with albinism holding a diploma, he said I did not know what a diploma was or a certificate, I was heartbroken. (Isaack, male graduate with albinism- LSES).

Ahmed asserts that people are often involved in the negotiation of boundaries between selves and others, and between communities, where others are seen as unlawful invaders or intruders (2004a: 136). By negotiating boundaries between our selves and others, Ahmed (2004a) says we can see other people as intruders. For this reason, she believes we often react to defend our territories from those we label as intruders. Thus the act of removing Isaack from the seat can be interpreted as the student's negotiation of school territories. In such negotiations, the student in question imagines Isaack as an intruder who has taken a seat or space without permission. Ahmed (2004a) terms such an imagining an emotional response of hate, which had bound a student to Isaack's seat. From such imaginings, the student had demarcated all seats as spaces that belong to students without albinism. This demarcation is confirmed in the student's question; he asks Isaack whether he had seen any people with albinism in secondary school. This question implies that the student had in mind the rightful occupants of the classroom space, who did not include people with albinism like Isaack.

Some people often feel more at home in certain places or spaces. Ahmed tells us that there are some bodies, which become understood as the rightful occupants of certain spaces (2012: 2), which are bodies at home. Looking at Isaack's reflections, there are implications that the respective student has a body that feels more at home. Bodies at home according to Ahmed (2000) have domination privileges and normative positions. Despite the very student being shorter and possibly physically weaker than Isaack, it is possible that domination privileges and normative positions held by the student were what enabled him to remove Isaack from the sit. I would say that the very privileges and positions possessed by the very student gives the student what Ahmed would refer to as

the rightful occupancy of certain spaces (2012: 2) which is the rightful of being the body at home.

The body at home, in this research is that of those without albinism. People with albinism therefore as indicated elsewhere are bodies that do not belong. This means that the school life of students with albinism can be intolerably difficult and thus affect their learning process. Lund (2000) who has done various study on people with albinism in South Africa and Zimbabwe, tells us that academic progress of students with albinism is often affected when their learning process is not well supported. She (2000) mentions ways of supporting students with albinism learning as sitting them in front rows of the classroom and near the blackboard and also enabling them to sit away from direct light. Such support in Isaack's case was not possible because there was a student who claimed a monopoly of the classroom space thus assuming a position of being at home (Ahmed, 2004a).

On the other hand, Isaack's removal can also be seen as a defence of space. Ahmed (2004a) talks about the defence of space from people seen as intruders. She gives an example of 433 people from Afghanistan who travelled by boat to seek asylum in Australia. On their arrival they were denied entry and removed from within the boundaries to protect Australia from intruders. This can also be said in the case of the student and Isaack. Upon arrival in the class the student saw Isaack as an intruder in the school space thus, defending that space, he removed Isaack thus making him to remain outside his established boundaries.

In defending spaces against intruders sometimes systems of violence can be produced. For example, Loveness, a female student with albinism with a middle-class social economic status (MSES) reflects on her experience and says:

(I) remember when I was in standard four, one street boy came to me with a blade and scratched my hand with it, and said that he wanted to see if my blood was green or red. (Loveness, female student with albinism- MSES).

Loveness implies the dehumanisation of the other. By inflicting pain on Loveness the street boy assumed that she was not human and therefore not sensitive to pain. Such assumptions have resulted in severe cruelty and inhuman mistreatment of people with albinism not only in Tanzania but also in other African countries. In Tanzania, for example, the Mwananchi Daily Newspaper recently reported about a woman with albinism whose hand was amputated and taken by a burglar (Kibada, 2015). In Burundi, a six-year old

girl with albinism was shot in the head and then the murderers amputated her head and limbs and left her headless and limbless body¹. Another brutal killing in Burundi was that of an eight-year old boy who was murdered in the presence of his mother and whose arms and legs were taken by the perpetrators. In Kenya, a woman with albinism was brutally killed and her eyes, tongue and breast were cut out (Gettleman, 2008). According to Ahmed (2004a) when people are dehumanised they are often compared to non-human objects. This could therefore mean that people who kill or amputate body parts of people with albinism do so because they do not see them as human. This is so because even UNHRC (2013) in its report on the experiences of people with albinism in some countries of Africa including Tanzania indicate that some people in Tanzania believe that people with albinism were not human.

Loveness talks further of the incident of the street boy and her feeling of being dehumanised and says:

(f)rom then on I began to be afraid of people. But my mother told me to be afraid of the sun than people, because the sun was my biggest enemy, before then I used to think my biggest enemies were people. (Loveness, female student with albinism-MSES).

The dehumanisation that Loveness and other people with albinism often endured made her see humans as her biggest enemies. Here Loveness sees herself as not part of humanity. This is not a good sign for Loveness and other people with albinism's learning process because such beliefs could not only affect their relationship with their fellow students but also their schoolteachers. Literature indicates the importance of a positive student-teacher relationship (Baker et al., 2008). Such relationships, according to Baker et al. (2008), are vital in the trajectory of students' formal schooling experiences as they provide students with a sense of safety and security in the school environment. Students' safety and security can promote positive academic attitudes and competency, which is important for learning processes.

Loveness like all the students with the condition in this study experienced bullying and harassment from other students. Therefore a good relationship with teachers was important for their retention in school. The bullying that Loveness talks about involved some students throwing her books outside in the hot sun where she could not collect them

¹ (www.economist.com/node/12948633)

because of her delicate skin. Bullying, according to the Tanzanian scholar Ndibalema (2013), is widespread in Tanzanian schools. But it is worse in students who are already marked as non-human like students with albinism in this study. For Simon, Lucas and Deborah bullying involved tearing their school uniforms and putting stones or rubbish on their desks. Ndibalema (2013) sees bullying as one of the reasons that some students were involved in excessive absenteeism and dropped out of school. Loveness talks about how she had planned to give up schooling. It was only after her parents had pressurised her and, as already mentioned above, after her brother repeated a year to be in her class with her that she continued with her learning.

Loveness is not the only student with albinism in this study who thought of dropping out of school. As already mentioned in Section 4.1, Isaack also dropped out of school for almost one year when he was in Form One, and involved himself in radio repairing and even in street dancing. Actually, he says that people who saw him at university were surprised that he entered HE. As for Lucas, he says:

(d)uring my A level education, I completed the whole term, which is three months, without going to school. This was because students were unfriendly and also I found that I could not see what the teacher was writing on the board and I had no support. So the day I went back to school my teachers were surprised and they told me that they thought I had dropped out of school. I was then taken to the head teacher and my name was written on the blackboard for being 'stubborn'. (Lucas, male graduate with albinism- MSES)

Although Loveness and Lucas, as well as the rest of the students with albinism in this study, proceeded to HE, the UNHRC (2013) says students with albinism often drop out of education, quoting the testimony of a woman with albinism who could not endure insults from her father, teachers and students and so decided to drop out of school and live on the streets.

Returning to my point about the dehumanisation of people with albinism, another participant who implies that people with albinism were dehumanised was Ester. Here she says:

(f)or them people with albinism are not pure. They are not human - that is how they believe so they should not be in society. (Ester, female NGO official).

In such views, albinism embodies impurity. Therefore, people with albinism are seen as violators of pure bodies (Ahmed, 2004) and thus should not be in society, so:

(i)n Tanzania many years ago every tribe - maybe even now - they had a belief that you have to murder a child at birth with albinism. This is a practice throughout Africa. (Ester, female NGO official).

The kind of belief that Ester talks about may relate to the notion of purity. Ahmed (2000) talks about how societies could malign people in an attempt to keep spaces pure. Purification systems, according to Douglas (2003), are sometimes enforced so as to keep social spaces pure from what is thought of as the pollution of people considered as not the norm or capable of contaminating societies. Therefore murdering of children with albinism could be a way of purifying society that they do not grow up to contaminate other spaces like HE. A purification practice that resembles the social purification on which Ester implies was the persecution of women as witches in ancient times (de Beauvoir, 2011[1949]). In Tanzania:

(t)he government designated centres to accommodate people with albinism. So there were centres at Kabanga, Kigoma; Buhangija, Shinyanga; Mitindo and Bukumbi in Mwanza; and then we had Missionaries of Charity and Furaha in Tabora; we had Kitengule and Mugeza in Kagera and also Pongwe in Tanga. (Ester, female NGO official).

The nine centres that Ester discusses were established countrywide in 2006 by the government to protect people with albinism, particularly schoolchildren, from killers and hunters of people with albinism's body parts. The killers were hunting people with albinism body parts as 'charms' for success and wealth (Tanner, 2010) only because they are seen as not pure.

The centres were meant to be boarding schools for children with albinism so that they could continue with their learning and at the same time be protected from attacks, which could occur on their way to or from school or in their homes. By being in protection centres, I can say children with albinism are made refugees in their own country. Morrice (2013), a scholar of the experiences of refugees in UK HE and whom I mentioned in Chapter Two, suggests that the experiences of being a refugee do not easily fade away. According to Morrice, refugee experiences often remind people of a sense of not belonging and exclusion because refugees are widely 'marked by both belonging and recognition, deficit and exclusion' (2013: 654). The experiences that children with albinism undergo are likely

to give them a sense of not belonging, or non-citizenship. Given that the experiences of being a refugee as Morrice (2013) emphasises do not simply go away, even when people with albinism are enrolled in universities, they are likely to feel the same, given that:

(w)hen we visited Buhangija we found that both adults and children with albinism were living in squalid conditions and conditions were really appalling. The school was not ready to accommodate more people. It was only meant for 30 children who are visually impaired but when we went there we found more than 105 children living in the same accommodation facilities. (Ester, female NGO official).

An environment that is conducive to learning is very important to promote students' academic achievement. The learning environment at Buhangija, which was not only reflected upon by Ester but also by other NGOs officials such as Philemon, Michael and Abraham, was not one that would adequately foster the learning or progression of students into HE. Given that there were 105 children with albinism, as well as several adults with albinism in a school which was designed to accommodate or cater for only 30 students with visual impairment, the school had a poor learning environment and also poor sanitary facilities for young girls with albinism. According to Ester, the Buhangija centre had four toilets, two for girls and two for boys, and four bathrooms arranged similarly. Adequate sanitary facilities are important for the retention of a girl child. A report by the Forum for African Women Educationalists (1998), for example, reflects upon the experiences of girls in schools and indicates that among the factors which affect their participation was the school environment, particularly sanitation facilities. As Buhangija has not only poor learning facilities but also poor sanitation, it constrains even further the learning process of a girl child with albinism.

Ester says 'the conditions were almost the same in all the centres that we visited'. Here, she implied that the centres were overcrowded and basic teaching and learning facilities and accommodation were not adequate to accommodate people they found there. This shows that the centres cannot be a conducive place for student learning. Ester cites an incidence of a mother at the centre who had five children with albinism, one of them being an 18-year-old daughter with albinism who herself had a child (I explain this in detail in Chapter Five). Such an environment provides this research with examples of the academic experiences endured by some children with albinism in their interaction with HE opportunities thus answering my fourth sub-question, which attempts to better understand

the life experiences of students with albinism's inclusion or exclusion in different phases of the education system. The life experiences of students with albinism are, I would say, no different to the experiences of most refugees whose displaced lives widely affect their full participation in both social and academic life (Morrice, 2013).

By being treated as refugees, the experiences of people with albinism do not differ from the experiences of asylum seekers upon whom Ahmed (2004a) reflects in the notion of affective economies. Ahmed (2004a) talks about asylum seekers in the UK who were waiting to be granted refugee status. In Ahmed's (2004a) view, asylum seekers are sometimes seen as a group that would impair properly-functioning systems. According to her, such assumptions may in some cases circulate anxiety. She gives an example of a highly-placed UK government official who showed traces of anxiety in his speech about asylum seekers, implying a link between asylum seekers and a loss of control, and thus warning inhabitants or homeowners or British nationals against such asylum seekers, who might take over their nation with the consequent loss to British national of control of their country. Ahmed (2004a) argues that this kind of threat to existence is likely to arouse anxiety in defence of it.

Although people with albinism were placed in centres for safety reasons, Ahmed's (2004a) notion of the defence of existence suggests that the placement is precisely this: people without albinism, who assume themselves to be the legal occupants of Tanzania, defend their existence by restricting the inclusion of those with albinism, who are seen as intruders. Thus, they believe, the former do not lose control of the land to intruders who might take over and become the occupants of the nation. Any attempt to include the intruders may circulate anxiety and inhabitants therefore defend their existence. Placing intruders in centres allows them to be closely watched and monitored so they do not threaten the legal occupants of Tanzania. In this context, the struggle for existence can result in less attention being paid to the basic and special needs of those seen as intruders, with the unsatisfactory living conditions at Buhangija and other centres being a consequence of this.

Anxiety over invaders does not only work to confine intruders in centres or asylum shelters but can also work in other places like schools and universities. A good example is the case of Meshack's head teacher upon whom I reflected above. In relation to Ahmed's

(2004a) notion of the defence of existence, that head teacher was attempting to ensure that the assumed inhabitants of school space did not lose control of that space. Meshack is not the only one who was removed from school by this defence mechanism. Ester mentions a list of five students with albinism she came across who were not in school because they were told that their schools cannot cater for their special needs. Likewise, Michael, who is a male NGO official, named three students he came across who were removed from school for similar reasons. In this context, I would say that defence of existence negatively impacts on the participation of students with albinism in all phases of education, including HE.

The struggle for existence does not only occur in schools but also in homes. For example, David says:

(m)y dad, I don't know where he is. Unfortunately, my dad is also among the people with negative perspectives against people with albinism. So when I was born with this condition my father left, simply because I had albinism, not any other reason. So he doesn't know where I am, and I don't know where he is and actually he makes no contribution to my life. (David, male graduate with albinism- LSES).

The Tanzanian culture is mostly patrilineal, meaning that children, whether daughters or sons, follow the father's line and belong to the father's kin. It is therefore possible that David's father would have preferred offspring who could ensure the continuation of his kin. Given that David threatens such a continuation because he is seen as not the norm, his father might have rejected him in order to defend the existence of his kin. As mentioned elsewhere, this may also be the case with the fathers of Happiness, Sarah and Angel, who also left when they were born, as well as with the fathers of Isaack, Thomas and Peter, who paid less attention to their needs, including educational needs and support. In this context, I would say that fathers of children with albinism reject their children with albinism in order to avoid the extinction of their kin.

In Chapter Two, I discussed the role that parents play in motivating or inspiring their children to interact with HE opportunities (De Broucker and Underwood, 1998). This means that parents' attempts to evade extinction can be a barrier to the inclusion of students with albinism in HE and may, in other words, be among the reasons for the exclusion of students with the condition from HE. When they are trying to avoid extinction, fathers cannot adequately play their part in motivating or inspiring their children to aim for HE.

4.4 The working of ambivalence

As already mentioned elsewhere albinism has contradictory meanings. On the one hand it is constructed as a 'bad omen' or curse; on the other, as a source of good luck or success, for example:

(p)eople with albinism are being hunted down not because they are a curse, but because people want to use their body parts in order to enrich themselves and be successful because that is what the witchdoctors have told them to do. (Ester, female NGO official).

Here Ester implies a dual meaning of albinism, where albinism is hate and love at the same time. Such ambivalence in human being was first described by Freud (1934a cited by Ahmed, 2004a: 354) to indicate the concurrent existence of love and hate in the same object. Here Freud attempts to describe the simultaneous presence of love and hate by analysing the relationship of the child and the mother's breast. He suggested that the child loves and hates the mother's breast at the same time because the child is interested in both libidinal and aggressive gratification. Ahmed (2004a) when theorising ambivalence argues that hate can sometimes be confused with and renamed as love. What Ahmed means here is that the value of success and wealth that albinism has now accrued could be confused with love because:

(n)ow people with albinism are being hunted down like wild animals mostly for their body parts just because witchdoctors have told their clients that the body parts of people with albinism can be used to enrich them or to make them successful. (Ester, female NGO official).

Ester is not the only participant who talks about the killings and mistreatment of people with albinism. Eliza and Philemon also talk about such killings and they also pinpoint to the witchdoctors who tell their clients about the wealth that the body parts of people with albinism possess. The love for albinism that witchdoctors display was likely to hide the presence of hate. The witchdoctors that Ester talks about resemble a group that Ahmed describes as 'the critics of hate group' (2004a: 117). The 'critics of hate group are those who act out of a sense of anti-ness or against-ness to those people who hate' (Ahmed, 2004a: 123). Like Ahmed's 'critic of hate groups', the witchdoctors delineate an anti-ness or against-ness to those people who hate albinism. This way, witchdoctors seem to conceal their hatred by indicating that albinism is no longer a curse but a blessing that brings wealth and prosperity whereas:

(i)f I am bad, I am bad, my bones are bad. If I am a curse to the society and even my hair, my bones, my blood is a curse to the society. How can I become a good thing when I am dead, but a bad thing when I am alive? (Ester, female NGO official).

As mentioned elsewhere, the emotions that circulate around albinism are contradictory and irrational because albinism is hated and loved at the same time. Ahmed (2004b) informs us that hate and love are intertwined, and sees hate as an effect of the failure of love. In this case, the love that the witchdoctors (critics of the albinism hate group) are propagating about albinism is tied to hate. This is because the value of success and wealth that albinism has accrued causes the pain and elimination of people with albinism. The UNHRC (2015) report mentioned in my introduction reveals that since 2000, when witchdoctors openly declared their love for albinism, there have been 151 attacks, of which 74 have been fatal. Such attacks have denied people with albinism's right to freedom of movement.

Referring to the love of albinism, I would say that despite the *Ujamaa* ideology which I have explain in detail in my introduction section, emotions of love have failed to a large extent to circulate on albinism so as to include those with the condition in the 'family-hood' that the first President of Tanzania, Nyerere propagated. In her notion of love, Ahmed (2004a) suggests that people can sometimes fail to love others because of lack of love from their nation. She then says when there is a lack of love from a nation people can be prompted to demand it. The demand for love according to Ahmed (2004a) was prompted after a nation had failed to deliver its promise of happiness. When a country fails to deliver happiness to its people it can mean lack of love. The lack of love can prompt self-love that aims to heal the self (Ahmed, 2004a). Going by this notion it could be argued that because majority of people lacked basic needs, Tanzania failed to show love: some people felt lack of love and promise for happiness (basic human needs). Thus without love or the promise of happiness some people have become desperate. According to Freud (1934a: 45-46 cited by Ahmed, 2004a: 125) desperation can turn into anacletic love, which he defines as self-love where the self is the primary object of love. I can say some people (attackers) in Tanzania have developed out of their desperation a self-love that seeks to heal the self with charms for success and wealth imagined in the body parts of people with albinism.

Ahmed (2004a) discusses self-love in terms of idealisation love. This kind of love, according to her, is based on the relation of having (see the definition of witchcraft in section 1.6). She here supports and quotes Freud (1934a: 45-46) who describes idealisation love as the over-valuation or exaltation of the object (Ahmed, 2004a: 127). In this way, love for albinism is the love of having, which could mean the love of having that, which would heal the attackers' desperation. In this case, albinism acquires positive value, not through any love for albinism but because of the love for the self. This means that the value of a source of success and wealth that accrues to albinism is for the benefit of the attackers of people with albinism and therefore should return to them. This implies that albinism has limited chances of acquiring value because of ambivalent emotions circulating on it by witchdoctors (see also section 1.6). Having no chance of acquiring value means having no chance of easing ambivalent emotions on albinism. Such persisting emotions continuously threaten the safety of those with the condition thus affecting their movement to and from their homes. When peoples' movements are confined, it means even their access to various opportunities including education is also restricted. This is an indication that ambivalence that circulating on albinism work to restrict students with albinism to interact with education including HE as it raise issues of security and safety.

4.5 Summary

This chapter was the first of the three chapters in which the findings of the study are presented and analysed. The data for this chapter came from 19 of the 35 participants whom I interviewed. The 19 participants included 14 students with albinism, four NGOs, one member of teaching staff and a mother of children with albinism. The major themes to emerge from the data of this chapter were emotions circulating around albinism, and symbolic violence. The key findings are summarised below.

People without albinism in the Tanzania are the majority. This gives them the power to dominate people with albinism, who are the minority. Within the context of this power of domination, I established that those without albinism often constitute elements of similarities, thus creating those with albinism as different. To maintain and sustain their power, people without albinism have used myths and beliefs not only to circulate various emotions which stick to albinism but also to impose their way of being as the legitimate way of being human in Tanzania. By legitimising their own way of being as the norm,

they assume humanity or normality and therefore see those who are not like them as deviant or non-human. They have thus used myths to label people with albinism as bad omens, ghosts, curses, sources of success and so on. As discussed and indicated by all the 19 participants, including the 14 students with albinism, this labelling has circulated emotions of fear, hatred, disgust, shame, pain and ambivalence, to mention a few. Such emotions constitute what Bourdieu (2001) calls symbolic violence as people with albinism are seen as strangers, stranger danger, intruders, non-human or not belonging. This invisible violence or emotions have in Ahmed's (2000; 2004a) terms, been 'sliding' from one generation of people with albinism to another.

Moreover, according to Ahmed (2000; 2004a), emotions work to join some people together and to separate them from others. In this sense, emotions that circulate and stick to albinism have worked to exclude people with albinism, constructing boundaries between people with albinism and those without albinism. Such boundaries have, to a large extent, worked to separate parents from their children with albinism, as indicated by Sarah, Happiness, David and Angel, who were all rejected by their fathers; and Peter, Isaack and Thomas, who were not rejected but were treated harshly by their fathers. Given such boundaries, some parents have also shown reluctance to invest in their children's education, believing they would receive poor returns, which suggests parents' misrecognition of the cognitive ability of people with albinism.

It is not only parents who sometimes misrecognise the cognitive ability of students with albinism but also teachers who, in some cases, regard them as lazy or stubborn, as confirmed by Sarah and Lucas. Archer (1984) in her book *Social Origin of Educational Systems* sees education systems as having a particular structure and relation to societies, and sees such structure and relation as determined by those in control. Parents and teachers have other roles in society, they can be decision-makers or university managers; therefore, when parents or teachers have negative perceptions of children with albinism, it can influence their decision- and policy-making as well as their practices. This results in government and university systems working as if students with albinism were not worthy of government or university investment.

While students with albinism experience various barriers in their interaction with HE opportunities, there is limited support provided to enable their learning and inclusion in

education. Schools and universities largely lack specific teaching and learning facilities to support the needs of students with the condition. Further some teachers have limited skills to teach students with albinism. Despite such limitations some teachers blame students for failing to cope with their ways of teaching. This indicates that a deficit model exists in our education system and impacts negatively on the participation of students with albinism in HE. This way, the system tends to focus on individual problems and thus overlooks structural constraints, such as teachers' teaching skills and availability of specific teaching and learning facilities, as well as the overall learning and teaching environment.

People with albinism do not only experience life as strangers, dangerous and bad investments; they are also seen as intruders. By being demarcated as intruders people with albinism are separated from those without albinism. This separation excludes people with albinism from almost all areas of social life and all phases of the education system. When systems perform exclusion, Ahmed (2006) says they fail to recognise certain groups of people. This may be the reason that limited support has been rendered to students with albinism, as their special needs are often not always respected and therefore limited efforts are made to support their needs.

Albinism as reflected upon throughout this chapter is widely seen as a 'deviant'. By being labelled as deviant albinism continuously attracts various emotions. Although emotions affect all people with albinism, as discussed in detailed in the following chapter, emotions affected differently women with albinism when compared to their men counterpart. Ahmed (2004b) tells us that some groups of people attract and stimulate emotions more than others. Women as discussed in the following chapter have for years been hated. This way, emotions that stick on albinism had attracted and stimulated emotions of hate on mothers who give birth to children with albinism, thus constituting misogyny which emerged as another major theme of this research. In this context, the following chapter is on misogyny. The chapter builds on Ahmed's (2004b) notion of difference by analysing how emotions work to constitute misogyny, which consequently impact on the education of students with albinism particularly HE.

Chapter Five

Blame the Women: Misogyny in Contemporary Action

5.1 Introduction

The term ‘misogyny’ originates from the ancient Greek word ‘misien’ which means ‘to hate’, and ‘gune’ meaning ‘women’. Misogyny, then, means hatred of women. In ancient days misogyny was a common phenomenon and reflected in some of the texts often written by men. Texts written in ancient Greek, for example those by Menander and Semonides of Amorgos widely display misogynistic characteristics (de Beauvoir, 2011[1949]; Trail, 2008). Menander’s poetic writing dehumanised women by defining them as monsters: ‘there were many monsters on earth and in the sea but the greatest of them all was still a woman’ (cited in de Beauvoir, 2011[1949]: 101). Semonides of Amorgos also had a tendency to devalue women by describing them as wicked: ‘women are the greatest evil God ever created: if they sometimes seem useful, they soon change into trouble for their masters’ (cited in de Beauvoir 2011[1949]: 101). Again, a text such as *The Malleus Maleficarum* (‘Witches’ Hammer’) by Heinrich Kramer and James Sprenger (1486), first published in 1486, has often been viewed as a representation of medieval culture and attitudes towards women. ‘Witches’ Hammer’ was used to justify the persecution of women and the widespread assassination of women thought to be practising witchcraft. These descriptions of women which de Beauvoir (2011[1949]) calls misogyny are not different from what I have discussed in detail in the preceding chapter, and which Ahmed (2000; 2004a; 2004b) refers to as emotions of hate.

Similarly, misogyny also exists in various religious ideologies. Eve, for example, in Judaism and Christianity, is believed to have been vulnerable to temptations by the devil and thus influenced Adam to sin against God. Eve was therefore then punished and cursed:

(I) will greatly multiply thy sorrow and thy conception; in sorrow thou shalt bring forth children; and thy desire shall be to thy husband, and he shall rule over thee. (Genesis, 3:16).

Such religious verses can circulate not only the vulnerability and subordination of women but can also have a serious impact on society. In Tanzania, for example, such a biblical

verse might have as recently as June 2014 influenced a male Member of Parliament to show misogynistic attitudes. The Member of Parliament was quoted by one newspaper as saying in parliament that in sacred books such as the Bible, God punished women and required them to be dominated by men (Habari-Leo, 2014). According to Habari-Leo (2014) the male MP made this statement to oppose a question raised by a female Member of Parliament about equal representation in the Tanzanian Parliament. Members of Parliaments in Tanzania are mandated by the constitution to enact and pass various laws. Therefore, if the Member of Parliaments mentioned above is the lawmaker, there are possibilities that some laws may show traces of misogyny, and work to continue the exclusion and oppression of women. This is especially the case when such lawmakers believe, think or assume that women should be subordinate to men. Such thinking is likely to jeopardise the interests of women, including those with albinism.

Going back to my discussion of various religions and their views of women, I would say that mythologies in religions such as Islam, Hinduism and Buddhism similarly express negative attitudes to women. In Islam, for example, the scripture texts sometimes construct women as weak and lacking ability, thus subjecting them to the strict guidance and protection of men. Marcus (1992), who has researched Muslim women in Turkey, narrates how women had to be under the protection of fathers, brothers or husbands. This, according to her, gives men the privilege of controlling and being in charge of women (Marcus, 1992) because, as de Beauvoir (2011[1949]) also argues, they are considered as not autonomous beings. Marcus (1992) also suggests that in Islam like Christianity women are often seen as 'impure' and dangerous, particularly when menstruating or after childbirth. Therefore when women are menstruating or have given birth they are not permitted to pray, touch their holy book or be involved in any religious activities (Marcus, 1992). Such restrictions can to a large extent oppress and limit women's freedom and their rights to freely exercise their faith or participate in religious festivals.

Hindu and Buddhist ideologies can be equally harsh and discriminatory against women. Dharma-sastras, popularly known as the 'the Rules of Right Conduct' or 'the Laws of Manu', is a sacred book to Hindus just as the Bible and Qu'ran are to Christians and Muslims respectively. In 'The Laws of Manu' (circa C.E. 200) there are basic rules for women's behaviour, which stress the need to control women because of their evil character (Wadley, 1977: 115-116). However, women in Hinduism have dual images: they can

be seen as evil and at the same time as good. Susan Wadley (1977), who has written extensively on Hinduism and women, says that in Hinduism, in times of prosperity in the homes of men, women are seen as 'Laksmi' the goddess of wealth, while in times of misfortunes, they are seen as 'Mariyamman', the goddess of misfortunes who brings ruin and death.

African traditional religions, as discussed in section 1.6, do not have written records and there is therefore limited written knowledge as to how women were viewed in ancient Africa. However, as already mentioned, African traditional religion was gender free and women were powerful. For example, Rodney believes that women's rights were a dominant feature in African societies, as they had real power which was exercised through religion (2011: 356). Rodney (2011) gives the example of the Rain Queen who was considered powerful in ancient Africa, and widely believed to bring success, prosperity and wealth. With such positive women images in African religions, it is possible that misogynistic tendencies in contemporary African were transmitted by foreign religions.

In a general sense misogyny is not an ancient practice. Beliefs that associate women with misfortunes and disasters still prevail in contemporary societies. For example, in Indonesia in 2005, immediately after the tsunami catastrophe, Meo (2005) quoted a *sharia* judge as saying that the tsunami was God's revenge on Indonesia for women's wicked ways. The 'sharia' judge therefore ordered that women who did not wear 'hijab' should be punished because their bodies were tempting men to sin against God. This type of scapegoating is misogynistic or, in Ahmed's (2000; 2004a) terms, it is an emotion of hate. In Bourdieu's (2001) view, on the other hand, it is symbolic violence as it blames women as immoral or promiscuous for men's inability to control their sexual desires.

Buddhist ideology can also exercise misogynistic attitudes towards women. A British female scholar, Horner (1930), who researched women under ancient Buddhism, also found traces of misogyny. Horner (1930) talks about the argument that Buddha refused to ordain women as nuns because he believed that by allowing women into the *sangha* (Buddhist monastic order) his teaching would survive for only 500 years instead of 1000 years (O'Brien, 1988). This could mean that women are distractors, thus can distract monks from the practice of Buddhism if they are allowed into the *sangha*. Horner (1930) also noted discriminatory rules and regulations applied to Buddhist nuns when compared

to those of Buddhist monks. One of the rules, according to Horner (1930) and O'Brien (1988), stated that a nun was not permitted to be on her own at any time, whereas monks were allowed time to be on their own for meditation. This restriction on nuns could be seen as a sign of mistrust of women, who are often considered promiscuous and whose sexuality should therefore be watched and controlled at all times.

Religious ideologies are powerful tools in shaping worldviews, beliefs and peoples' behaviours. Therefore, when religions have misogynistic traces (de Beauvoir, 2011[1949]) or in other words circulate emotions of hate or fear about women (Ahmed, 2004a) or imply symbolic violence (Bourdieu, 2001), there are possibilities that such misogynistic elements can stick to women. Societies are therefore likely to have negative perspectives of women, which are likely to affect women's social, economic and/or educational opportunities.

Beside religious ideologies, some ancient philosophies also featured misogyny. Aristotle, for example, wrote that women were inferior to men (Freeland, 1998). According to Freeland (1998), Aristotle referred to women as having fewer teeth than men and stated that they were incomplete or deformed men. Aristotle's allegation could be particularly dangerous for the image and status of women because he was a well-known and respected scientist, whose theories could easily be taken to be correct.

A more recent theorist who can also be seen as a misogynist and who has tarnished the image of women was Sigmund Freud. Freud, a renowned psychoanalyst, believed that 'women were castrated by nature' (Greer, 1970: 119). Aristotle and Freud were both respected philosophers in their time and their theoretical perspectives and arguments have been quoted, cited, respected and believed by various people and societies worldwide. Their negative suggestions about women could therefore have serious repercussions, not only to the societies but also to women themselves as some women could internalise such negative beliefs and see themselves as inferior to men. Referring to what I had mentioned in my introduction chapter, Morley (1992), reminds us that internalised oppression can feed us with a sense of failure. This sense of failure can affect our full participation in HE, as it is likely that with such feelings we will see ourselves including women with albinism as incapable of it. Internalised oppression can also sometimes influence women to feel that they are not capable of pursuing certain courses such as mathematics or sciences.

Medieval texts, religious mythologies and philosophical notions can influence contemporary cultures and traditions. To a large extent medieval cultures and traditions often portrayed women as characteristically immoral and sinful. Women were also considered as having limited cognitive ability, as being physically defective, unnatural and monstrous, and as having deviated from the laws of nature. Horner (1930) suggests that women were regarded as being between men and animals. As a point of emphasis, Ahmed (2004a), in her notion of affective economies which I discussed in detail in Chapter Four, says that when one person dehumanises the other, the first person often compares the second with non-human objects. When women are regarded as between men and animals all women are therefore being dehumanised.

As I have shown, in medieval texts, religion and philosophy, and even in the studies and beliefs of contemporary times, women have been widely perceived negatively. They have often been viewed as chaotic, formless and dangerous, and men's bodies have been seen as the universal norm (de Beauvoir, 2011[1949]; Irigaray, 1985). This circulating hatred positioned women as 'others' and constructed a patriarchal culture, which often privileged men over women by spreading masculine myths of male superiority (de Beauvoir, 2011[1949]; Greer, 1999). Emotions like those circulating on albinism, discussed in Chapter Four above, have been passed on from one generation to the other. Likewise it seems misogynistic tendencies about women have been circulating from one generation to another. However, earlier archaeological evidence indicates that circa 6000 B.C.E. some societies could have been matriarchal, for example, Catalhoyuk in today's Turkey (Mellaart, 1960). Thus showing none misogynistic societies.

Misogyny has widely been associated with men, but of course women can also practise misogyny against other women. In this particular study, Eliza discusses incidents in which she experienced a negative relationship from two women, which could be interpreted as female misogyny between women (Mavin, 2006). But women's misogyny has been widely associated with the oppression and devaluation that women often encounter in their lives (Williams and Giles, 1978; Skevington and Baker, 1989, cited in Morley, 1992). This means that women can sometimes hate other women because of the beliefs and myths that portray women negatively, this negativity having been internalised in their minds.

Internalised negativity can sometimes result in women preaching or teaching misogyny to other women, including young women. I remember, for example, that during my childhood I was taught by my mother who was a 'Haya' by tribe that it was a 'bad omen' if the first person I met on entering a public space was a woman. Such a patriarchal myth could, as I realise now, have meant to restrict women from public spaces. I do not know what such myth could have done to the minds of other people, including women belonging to the Haya tribe, but I know that in my case it has left a lasting impression. 'The very reach of the past shows that it was not one I had left behind' (Ahmed, 2012: 2).

Misogynistic experiences often faced by women and pinpointed by Simone de Beauvoir (2011[1949]) and other feminist scholars such as Rich (1976), Greer (1999) and Morley (1992) are no different to the emotional experiences that Ahmed (2000; 2004a) talks about. Both misogyny and emotions separate people, thus constructing those with less power as others or non-human. Given the long-lasting negative representations of women in most religious, cultural, philosophical and psychosocial perspective as pinpointed above, the birth of children with albinism who are circulated with emotions of hate and fear, is often received negatively thus activates misogyny towards mothers, resulting in their birth being blamed on women. Likewise, because of misogyny, although both women and men with albinism are marginalized, mistreated and discriminated against, women with albinism seem to be worse off than their male counterparts. Baker et al, (2010), for example, in their study on *myths surrounding people with albinism in South Africa and Zimbabwe*, quoted their male participants as saying:

(t)o be person with albinism is a terrible thing but to be a girl with albinism is the worst of all (Baker et al., 2010: 176).

This research does not differ from the findings of Baker et al. (2010). My research found that women with albinism were seen as worse than their male counterparts. The 20 participants that I interviewed, including female students with albinism, talk about the hatred, blame, harassment, and abuse that women with albinism specifically experienced because they were women. For example, as stated above Philemon and Michael, both male NGO officials, talk about how women with albinism were often subjected to rape because of myths. Likewise, Elizabeth, a female teaching staff, talks about how the harassment faced by one female student with albinism at her university was so great that she decided to commit suicide. Angel and Sarah, both women with albinism, talk about

their experiences of being sexually harassed and abused. In Sarah's case, she talks about how she was sexually exploited and then abandoned when she became pregnant. Eliza did not only talk about the negative experiences of Women with albinism but also her own negative experience as a mother of children with albinism. The specific experiences of women with albinism, as well as of mother of children with albinism, frequently emerged from my data and it became apparent that misogyny as a theme was a factor influencing the participation of students with albinism in HE. This chapter therefore suggests that misogyny as a notion can enable us to understand the participation of students with albinism in HE. This understanding provides us with explanations as to how both women with albinism and men with albinism interact with HE opportunities.

5.2 Mothers' limited support: who is to blame?

Various literature suggests that children with albinism are often brought up by their lone mothers (Baker et al., 2010; Lynch and Lund, 2011) and the sub-theme of mothers frequently emerged in not only the data from the four students with albinism who were brought up by their mothers, but also in the data of other students with albinism in this study. In Tanzania, women widely have limited educational attainment, lack formal employment opportunities and thus have limited financial resources. The mothers of students with albinism in this study are likely to have had these experiences. For example, the mothers of the four students with albinism had either no formal education, or only primary education, and were in informal employment, which meant having limited financial resources. In UK terms, they would be characterised as working-class or lone parents.

As mentioned in the introduction, some literature from the UK, for example, Bauman (2005) and Lewis (2010), blames the non-participation of working-class students on their parents. Such literature often blames working-class parents for having home environments or facilities which do not support positive learning or encourage aspirations towards educational achievements for their children. It is possible that similar blame could be directed at mothers of children with albinism who lack the home environment or facilities to adequately support their children's learning. However, Francis and Hey (2009) see this literature as drawing upon a deficit model; they focus on individual problems and thus overlook structural constraints such as financial, institutional or societal ones. Given that

my sub-question two looks at the barriers and enablers to the participation of students with albinism in HE with the intention of understanding, among other things, the role of parental support, this section looks at misogyny and how it impacts on the support that mothers of children with albinism render to their children. This will, I believe, enable me expand my understanding and explanation of that sub-question.

De Beauvoir (2011[1949]) held that in patriarchal societies women widely suffer because of misogyny. In Tanzania some mothers particularly those with disabled children as shown above have widely been responsible for the care of their children. Some records in Tanzania indicate that some fathers reject their children with disability and leave the entire responsibility for them to mothers. For example, statistics released by National Survey on Disability (2008) reveal that in Tanzania nine per cent of children with disability under the age of 18 years lived without their fathers, as compared to 1.8 per cent who were living without mothers. Thus showing that women often carry the responsibility of supporting their children with disability.

In Tanzania, the Demographic and Health Survey (2010) reveals that households are often financially supported by fathers; fathers, therefore, contribute in determining educational participation. Given this, the absence of fathers may hamper the participation of some children in education. The four students with albinism who were abandoned by their fathers reflect on the struggles of their mothers in bringing them up. Here, as mentioned above, they talk of their mothers as having no formal education or of being primary school leavers with an income too unstable to adequately fund their daily basic requirements, let alone their school requirements. The four students with albinism say that they progressed to HE because they were supported by extended families. Angel was supported by her paternal aunt, David by his maternal uncle, and Sarah and Happiness by their grandmothers. David clarifies this point, saying:

(w)hen I completed Standard Seven my mother could not afford to pay for my Form One. I stayed at home for three months until my uncle decided to pay for me. (David, male graduate with albinism- LSES).

However, being unable to adequately provide David with a home learning environment or facilities that would support his education does not mean that his mother was irresponsible or lacked ambitions, as Bauman (2005) would have us believe. The minimal material

support that David's mother and mothers of the other three students with albinism could offer their children can be seen as a consequence of misogynistic structures which give women limited education and formal employment prospects, as explained in detail below.

Although Ester and Philemon, both NGO officials, talk about the suffering that mothers of children with albinism often endure and how it affects the education of children with albinism. In Tanzania Ester gives an example of a child with albinism who was being sponsored by the NGO that she works for. The NGO decided to fund the respective child's education after his father had abandoned him and the mother could not support his education. Then Ester talks about two women one of them being the mother of the respective child who were abandoned by their partners for having children with albinism. One of these partners was a university professor while the other was a prominent businessman in Tanzania, demonstrating how the link between alien and albinism has entered the heads and infiltrated some Tanzanians (Ahmed, 2000) irrespective of their level of education and economic status.

Given that fathers often reject children with albinism, it means that mothers often take the responsibility to bringing them up. Greer, in her book *The Whole Woman* asks '(i)s motherhood a privilege or a punishment' (1999: 3). Grimshaw (1986) says being a mother is unpredictable because it can be the source of greatest joy or the root of women's worst suffering. To Eliza, who is the mother of children with albinism:

(i)t is a struggle having a child with albinism in this world - it is not easy. It was very painful, very painful indeed. (Eliza, mother of children with albinism).

To Eliza being a mother means hurting, and common sense holds that hurting is not a healthy sign for personal wellbeing. Thus being a mother can be a sacrifice that some women make for the respect of the natural world (Rich, 1976). Unlike the mothers of the four participants I have mentioned above, Eliza was not abandoned by her husband when they had children with albinism. She says he was understanding and supportive. But she says that being a mother:

(y)ou lose a lot of friends because people are afraid of coming to your house and you have pretenders who are going to pretend that they are your friends but actually they are not. They will come only when they have a need and something like that. (Eliza, mother of children with albinism).

Traditionally in Tanzania, when a child is born it is a source of joy and happiness to family members, neighbours, friends and relatives. Due to such joy, neighbours, friends and relatives often visit the new born with presents and good wishes. But myths and beliefs, as explained in previous chapters, hold that when a person without albinism meets a person with albinism then the former is subsequently likely to have children with albinism. In cases where someone meets a person with albinism by accident then that person has to spit down to push out the albinism (see Chapter Four). For Eliza, these myths and beliefs meant being a mother was exclusion, loneliness and a sacrifice that she had to make because:

(p)eople say children with albinism are born because of some mistakes that mothers had committed like having love affairs outside wedlock. (Eliza, mother of children with albinism).

The stereotype that Eliza talks about links mother of children with albinism with immorality and sin, which is harmful to their identities. De Beauvoir (2011[1949]) says that even when things were changing and women's rights are widely respected and recognised, long-standing perceptions of women can prevent these rights from being practised effectively. Although it was scientifically proven that children with albinism are born after both parents have the albinism recessive gene, mothers of children with albinism continue to be accused and blamed. This, according to de Beauvoir's theory, is because of the long-standing view that women are in the wrong. Eliza was continuously seen as immoral and sinful.

These misogynistic accusations do not only leave a sticky stain on Eliza's life, but also on that of her children, who can be labelled *illegitimate children*, since such terms still exist in some areas in post colonial Tanzania. This seems to be a vice versa type of experience where Eliza and her children stain and contaminate each other. This can mean that emotions of hate that stick on albinism as discussed in Chapter Four can instigate misogyny, which always sticks on women thus indicating what Ahmed suggests that 'hate cannot be found in one figure' (2004a: 119). This means that the hate or, in other words, misogyny that Eliza experiences is not an individualised experience but the general experience of women and, in particular, mothers of children with albinism.

Ester, a female NGO official, talks about how mothers of children with albinism are associated with having sexual relationships with 'evil spirits' or being promiscuous.

Likewise, Eliza says:

(w)hen they talk maybe they say ‘you have sinned, you went to a European person’. You say ‘no, I know this is my husband’s and I haven’t been anywhere else.’ (Eliza, mother of children with albinism).

The devaluation of mothers of children with albinism experienced by Eliza is not only happening in Tanzania but also in other African countries. In Uganda, for example, according to the American researcher Allen (2010), mothers of children with albinism are seen as being impregnated by the ghosts of colonialists. In South Africa, mother of children with albinism are accused of having sexual relationships with ‘tokoloshe’ (Bourdillon, 1987; Murphy et al, 1988; Baker et al., 2010). In Zulu mythology, ‘Tokoloshe’ was a mischievous evil spirit that was called upon by malevolent people to cause trouble for others (Bourdillon, 1987). Associating women with such immorality and sexuality can be a way to prove the evilness and promiscuity of women and thus justify the male domination and control that is often imposed on them. As it will seem that women cannot control or manage themselves, it will also seem that they should ‘always be under men’s guardianship’ (de Beauvoir, 2011[1949]: 83) and monitoring.

Elaborating further her experiences of being a mother Eliza sadly discusses an incident when she was walking with her children. Some other children mistakenly thought her children were Europeans and called their mother to come and see them. But when their mother saw Eliza’s children she replied that Eliza’s children were not Europeans but ‘ghosts’. Referring to her experience, Eliza says that she asked the woman how she would feel if she herself had children with albinism, and painfully remembers the reply as:

(y)ou must be kidding, how would I get such children? Is there any mistake that I have done? Is there anything I have committed wrong or a mistake in front of God? This is a punishment from God. (Eliza, mother of children with albinism).

Contrary to the pride that Rich (1995) attached to motherhood, for Eliza it was street bullying and harassment. Such bullying and harassment does not only affect Eliza’s wellbeing but also limits her freedom and rights in public spaces. These limitations can affect the ability of Eliza and other mothers to overcome the constraining structures that are often imposed on them (McNay, 2000). This further limits their ability to motivate and inspire children with albinism and provide them with an adequate home learning environment and facilities to enable them to interact with HE opportunities. To blame

mothers of children with albinism in this study as irresponsible for not providing a conducive environment for their children learning would therefore be to overlook the misogynistic tendencies and other structural and cultural factors that constrain their abilities to adequately support their children's education.

Ester reflects on suffering of some mothers and describes the experience of a mother of a daughter with albinism (pseudonym Rita). Ester relates how the mother, desperately seeking Rita's treatment for terminal cancer, had to travel several kilometres by foot to take Rita to an eye clinic that was specifically for schoolchildren with albinism. According to Ester, Rita had been receiving limited health attention at the village clinic she was attending. Talking about Rita, who was illiterate because of her mother's poverty, Ester says her father rejected her at birth. Rita's father was a prominent businessman in the region where Rita, now deceased, and her mother resided.

Although Ester's reflection does not directly refer to the participation of students with albinism in HE, the struggle of Rita's mother to ensure her daughter's well-being is an indication that Rita's illiteracy is not a result of her mother's irresponsibility or lack of motivation to take her to school. This means, as Archer (2000) would argue, that it is a result of the long-dead who instigated misogynistic practices through some religions and philosophical beliefs. It is obvious that had she had the material means, Rita's mother would have provided her daughter with educational support, as Ester's reflection demonstrates that she was motivated to encourage her daughter's well-being, including her interaction with educational prospects. The actions of Sarah's mother indicate the same: she had had primary education and in the absence of adequate financial support she had used moral support and enrolled for secondary education as a private candidate so as to motivate Sarah to re-sit her Form IV examination, which enabled Sarah to proceed to Form VI and consequently HE.

Likewise, David's performance and entry into HE were supported by his mother's encouragement and motivation. As David says:

(I) was motivated by my mother to aspire for higher education. She used to tell me, my son I know you have many challenges, but work hard because when you succeed your challenges will be minimised and you will be a role model to others. (David, male graduate with albinism- LSES).

David's mother, like Sarah's, could endure the challenges that she experienced but it can be hard for others. Therefore:

(w)hen the child with albinism wants to go to school, the mother would not let the child go and if she allows the child to go to school she is not going to take time to see the progress, to follow or monitor the progress of a child. Because why would a woman invest in the education of a student with albinism knowing that this is a curse? (Ester, female NGO official).

When we are hurt whether emotionally or psychologically, according to Rich (1976; Carlson 1989 cited in Morley, 1992: 518), emotional or psychological hurt can take time to be healed. This can influence our actions or decisions. This way Rich (1976 cited in Morley, 1992: 518) comes up with a notion of the 'unhealed child'. The 'unhealed child', according to Morley (1992), is full of blame and hurt, which can be transferred to others. Morley linked and discussed the reactivation of the 'unhealed child' within women in a programme on women's studies in the UK, where painful memories of women's oppression can be transferred to others. In my study, the painful memories of the accusation, discrimination and dehumanisation of mothers that Ester is talking about are transferred to their children.

The 'unhealed child' can have an impact on the education of students with albinism and children with albinism. Eliza reflects on an occasion when she had organised a ceremonial gathering at a rented hall and invited neighbours, friends and relatives. She says:

(I) was sitting at the back because I normally sit in the back seat because I know people are going to talk a lot. (Eliza, a mother of children with albinism).

In Eliza's action one can say there are traces of 'unhealed child'. Such traces push Eliza to protect her children from the public gaze. The protection that Eliza attempted to impose on her children by sitting at the back could hide them and limit their interaction with education opportunities. This can be an indication that the hurt endured by mothers of children with albinism can influence them to hide their children, not because they are not motivated or unambitious but because they want to protect their children from the 'talking a lot'. Writing about the education of children with albinism in South Africa and Zimbabwe, Baker et al. (2010) reveal that parents in Zimbabwe were hiding their children with albinism at home. This means that emotional and psychological hurting

often endured by mothers of children with albinism can be a barrier to the participation of students with albinism in all phases of education, including HE.

Although I have discussed the abuse, harassment and mistreatment specifically of mothers of children with albinism, various literature (World Health Organisation, 2005; Berton, 2008; Smee, 2012) reveals that some women in Tanzania experience sexual gender-based violence, including rape, abuse and harassment, and intimate partner violence. The World Health Organisation Report (2005), for example, puts the prevalent rate of intimate partner violence against women in Tanzania at as high as 87 per cent in Mbeya and 41 per cent in Dar es Salaam. The high rate of violence against women in Tanzania is an indication of misogyny, as Dworkin (1983) suggests that misogyny can be conveyed through acts of denigration and intimidation (p.201). This is an indication that, in Tanzania, misogyny is not only experienced by mothers of children with albinism or women with albinism but also by other groups of women.

Furthermore, although in this thesis I have specifically argued that fathers often abandon mothers of children with albinism, literature shows that in Tanzania, other mothers also experience similar abandonment. For example, a study by Smee (2012) on violence against women in Northern Zanzibar indicates that in Zanzibar, 36% of women were abandoned and neglected by their intimate partners. These findings are an indication that the abandonment of mothers of children was not confined to mothers of children with albinism in Tanzania. What is unique, however, is that mothers of children with albinism were widely blamed for albinism, and that this was seen as a reason for their abandonment. Thus, misogyny is easily summoned and provides a ready-made vocabulary and belief system for blaming women for albinism.

Implying the unique experiences that mothers of children with albinism often face, Ester discusses an incident involving two mothers, (pseudonym Helena and her daughter, Selina) in one refuge centre in Tanzania. The centre, as explained in Chapter Four was destined for schoolchildren with albinism during the widespread killing of people with albinism, Ester says:

(w)hile Helena was at the centre seeking refuge for her five children with albinism, her husband at home in [name of the area] wanted her to go back because it was farming season. But how could she leave with her own child with albinism to go

back to the village because she could be attacked. So, what she decided to do was to swap the children. So she took the grandchild without albinism who was over a year old with her and left her own child seven months old with Selina, so Selina had to breast feed her own sibling and she had to breast feed her grandchild. These were situations that we found in almost all the nine centres that were destined for people with albinism. (Ester, female NGO official).

As discussed in Chapter Two, parents, including those in Tanzania, have a great role in motivating their children to interact with educational opportunities through their direct involvement in their children's education or by being role models. In this context, looking at the educational background of Helena, who is confined in a centre with her five children with albinism, it is apparent that her contribution towards motivating her five children with albinism as a role model is minimal. However, her minimal contribution as a role model does not mean that she is irresponsible, unmotivated or unambitious for her children's educational success (Reay, 2009). It means, rather, that structural constraints have contributed to Helena's situation and minimised her ability to be a role model (Francis and Hey, 2009). In this way, misogynistic constraints, which often limit women's success, can also limit the interaction of students with albinism with HE opportunities because students with the condition particularly women with albinism often have no role model to emulate.

5.3 Women's poverty: a barrier to students with albinism inclusion in HE

De Beauvoir (2011[1949]) says patriarchy continues to oppress women because of their economic poverty. Worldwide, the majority of women live in poverty. In 1978, when poverty was rapidly becoming a problem among women in the USA, Pearce (1978) coined the notion of the feminisation of poverty. This notion was later adopted and extended by Chant (2006) to incorporate women worldwide. Now feminisation of poverty, as defined by Chant, means that women represent the majority of the world's poor and that poverty among women is increasing, and also that women's increased poverty is caused by the rising female household headship (FHH) (2006: 203). In this study at least four participants, David, Happiness, Sarah and Angel, who were all from FHH, as repeated indicated, talk about their mothers' financial struggles to support their educational needs. Angel as mentioned above, who went to live with her aunty, as her mother could not afford to enrol her in school, says:

(w)hen I was in my high school the school fee, which was compulsory, was approximately Tshs 250,000/- [£90] that included all school contributions and uniform. Because I had no money I was late to report for school as usual. I was expected to report for school in May and I reported in June but the money that my aunty gave me was only Tshs 80,000/- [£29] out of the required Tshs 250,000/- [£90]. So what I did was that if someone would give me some money I would use it to pay for my school fees. I did that until I completed my high school. (Angel, female student with albinism- LSES).

What Angel says implies the existence of FHH poverty among some mothers of children with albinism and how it can impact on opportunities for interacting with HE. The other three participants under FHH also talk about their mothers' poverty. As already indicated above as for David a male graduate with albinism with LSES, indicates that it was only because he attended public schools for high school secondary education, as well as having financial support from his uncle at his ordinary level education, that he interacted with HE opportunities. Sarah a female student with albinism and Happiness female graduate with albinism both with LSES associate their pre-HE education with financial support received from their relatives, while they link their HE education participation to their relatives, friends and the government student loans that they received.

Elaborating further about their mothers' education and employment, Angel says that her mother never attended school and was a peasant, while David and Happiness indicate that their mothers were primary school leavers and small-scale businesswomen. Sarah, says: (m)y mother is a primary school leaver. She is unemployed so she stays at home and I have no father; he rejected me when I was born. (Sarah, female student with albinism- LSES).

De Beauvoir (2011[1949]) tells us that world resources are not distributed equally between women and men. She sees men as having better jobs, more education, higher wages and greater chances to succeed than women. What Sarah and the other three participants say about their mothers' backgrounds can be an indication that women in Tanzania still have limited access to education, formal employment and financial resources.

In the contemporary world, women are not only widely lacking access to education, employment or well-paid jobs, but they are also unemployed or in low- paid employment.

In Tanzania, for example, 66 per cent of women are in unpaid domestic work (International Labour Organization, (ILO) 2001). Even when women succeed in obtaining HE their chances of succeeding are still minimal compared to those of men. For example, a study conducted by the ILO (2001) revealed that when compared to men, women in Tanzania formed a higher proportion of those who receive HE training but were unemployed (ILO, 2001). This means that even when women are educated and have skills they have limited chances of succeeding.

Furthermore, studies have indicated that even when women are in employment they are in jobs that often pay them less as compared to men. The World Development Report (2013) suggests that globally men are more likely to have well-paid jobs than women. For example, the ILO (2010) survey that was conducted in 83 countries revealed that women in paid work on average earn between 10 per cent and 30 per cent less than men. De Beauvoir, (2011[1949]) tells us that women cannot be free from oppression unless we equally share with men the distribution of resources. But studies indicate that misogynistic factors often place women in low-paid jobs such as retail (ILO, 2010). Even when they are in agriculture, according to the ILO (2010) they often cultivate less; and when in business they are more involved in small-scale businesses. Such data do not only inform us that women like the mothers of Sarah, Angel, Happiness and David are excluded from economic opportunities through misogyny but also explain why they were kept on the margin and thus had to struggle to enable their children to interact with HE opportunities. These unnatural differences between women and men, according to de Beauvoir (2011[1949]), are among the reasons that women lack power to act, and justify the undermining of women so they cannot be economically independent.

In terms of education, women are even worse off. The UNESCO (2009) report on global literacy showed that 64 per cent of the 793.1 million illiterate people globally were women. In Tanzania in 2010 approximately 20 per cent of women aged 20 to 24 had no formal education at all, compared to 9.6 per cent of men (Demographic and Health Survey, 2010). The low percentage of women in education is often linked with cultural practices, which prioritise the education of a boy child over a girl child (Morley et al., 2006). Prioritising the boy child's education means that when there are limited funds, preference would definitely be given to a boy and if one child must drop out of school, it will be the girl, thus limiting the chances of a girl including those with albinism to interact

with HE opportunities. In this study, the mothers of all the 14 students with albinism except John had pre-university education, with five having had no formal education, six having had primary education and two having had 'O' level secondary education.

In term of women's enrolment in HE, Morley's et al (2011) study on WPHEGT reveals that the percentage of women applicants, who of course include women with albinism, accepted in universities was significantly lower than that of men, even when a high proportion of women reached the minimum standard to enter university. Even when women are the majority in HE, as in the Global North, they are widely enrolled in low-marketable programmes which can result in less well-paid jobs (Morley, 2006; Grenz et al., 2008). This study found that except for Grace, and Loveness who were enrolled in high-marketable programmes (see Table 1 and 2 in Section 1.2), the rest of the six female students with albinism who I interviewed were enrolled in low-marketable programmes, which might direct their future prospects to less well-paying jobs.

Lack of property inheritance or ownership among women can also be a reason for feminisation of poverty. In some countries in the Global South, including Tanzania, laws, policies and/or 'misogynistic' traditions restrict women's inheritance or ownership of property or land. Although the 1999 Land Act of Tanzania gives Tanzanian women the right to obtain and own land and also mandates the joint titling of land between partners, the prevailing 'patriarchal' Customary Law (declaration) order number 436 of 1963 tends to discriminate against women with respect to inheritance. Under this declaration, women and girls are not permitted to inherit clan land at all. For other types of property such as houses, women and girls might inherit, but less than their male relatives (Demographic and Health Survey, 2010). Given that at least 85 per cent of Tanzanians live in rural areas, the denial of land to women means subjecting mothers of the four participants under FHH to poverty and oppression.

5.4 Paying for invading public space

Sexual harassment, according to Greer (1999), is based on hatred and resentment of women's bodies. An analysis of the National Crime Victimization Survey (2007), for example, reveals that in the USA, disabled women had a high victimisation rate compared to their male counterparts, or even to non-disabled women. This could also be said of

disabled women in Tanzania, including those with albinism. In this particular study, female participants such as Angel, Sarah, Loveness and Happiness reflect on incidents that indicate traces of harassment and abuse. This is an indication that experiences of people with albinism are gendered, as women are treated more harshly than their male counterparts. Women with albinism do not only endure the stigma that all people with albinism often endure, but also the ‘othering’ and misogyny that women often encounter.

Women with albinism also face gender-based violence and hate crimes in the form of rape, as indicated by Philemon’s quotation in Section 4.1. Dworkin (2000) defines rape as an act of hate and revenge and suggests that it includes assault, battery, torture and kidnapping. This means that rapes that some women with albinism endure are acts of hate and revenge imposed on them. These misogynistic acts do not only physically hurt women with albinism but also affect their psychological and emotional wellbeing. Worse still, the violence and hate crime also subject them to infectious deadly viruses, some of which at the moment have no cure: HIV/AIDS and other sexually transmitted diseases. In their study, Baker et al (2010), reveal that women with albinism in Zimbabwe complained that men with HIV/AIDS were raping them and that some of the women had been infected and were dying from the disease. Such experiences do not only specifically limit the pool of women with albinism entering HE but also affect academic learning and personal wellbeing when we compare them to their male counterparts, who do have such experiences.

Again, rape threats to women with albinism can raise their anxiety about their personal safety, not only constraining their freedom of movement but also impeding their participation and/or retention in education, including HE. Samwel, a male government official who works in a section of the MOEVT that oversees policy and practice issues concerning disabled students’ in schools, says:

(c)laims that women with albinism cure HIV/AIDs were a challenge to the attendance and retention of our girls in schools particularly in villages, where they sometimes have to walk long distances and even sometimes alone or with other children who themselves are helpless. (Samwel, male government official).

Samwel implies insecurity and limited safety of women with albinism in public spaces, reflecting what de Beauvoir (2011[1949]) refers to as the consequences of living in a body which is the object of another’s gaze. The consequences of being in another’s

gaze involve, as she points out, being an objectified character. Ahmed (2000) associates objectification of character with fetishism, which means being devalued or having one's humanity being denied. When women with albinism are gazed at and raped, therefore, it means they are dehumanised and subjected to pain, as discussed in detail in Chapter Four.

Letherby suggests that 'silence is as important as noise in research and the interpretation of silence is as important as the interpretation of what is being said' (2003: 109). Although none of the women with albinism that I interviewed in this study talk about being raped, or rape attempts, going by Letherby's (2003) notion, I cannot certainly rule out the possibility of rape cases such as those that Philemon in Chapter Four and Samwel in this chapter reflected upon. This is firstly because sexual violence among disabled women is high (Mirrlees-Black, 1999 cited in Emerson and Roulstone, 2014: 3089); secondly because in some African cultures there is often a taboo against speaking about gender violence (Morley et al., 2006; Morley, 2011) and lastly, because violence often shames the victim (Dworkin, 2000). It is then possible that the taboo and feelings of shame could have prevented the women with the condition interviewed in this thesis from talking about their rape ordeals. These imposed taboos are exercised as cultural traditions and, I would say, are meant to threaten women so that they do not disclose the ruthless acts. This allows these acts which, to a large extent, benefit men to continue unreported (see Section 1.6).

Having Letherby's (2003) notion in mind I do not assume the absence of rape cases in my study. This is because the study by Morley et al. (2006) of five Commonwealth countries including Tanzania revealed incidents of rape on some university campuses. The later WPHEGT study (Morley, 2011d) also found the widespread existence of sexual harassment on campus. The sexual harassment and abuse of women, according to Stanko (2005), often changed their worldviews and made them more vulnerable. This could therefore be an indication that rape and gender-based violence can be a threat for the participation in university life of women with albinism.

While no incidents of rape were reflected upon, Sarah, Loveness and Happiness talk about the sexual harassment that they have encountered. Sarah had successfully obtained admission to one university in Tanzania but due to her financial inability to supplement her student loan she dropped out of university after it raised its tuition fees. Sarah therefore

stayed one year out of academic activities while working out her future. During that period she says she had an intimate relationship with a male who proposed marriage. However:

(a)fter being pregnant that is when I came to realise that he was married and he had two children and that he only wanted to benefit from my albinism. You know in 2008 many organisations were financially assisting groups of people with albinism due to a lot of killings. I think he thought that in one way or another by being with me he would benefit financially. But when he realised that what he wanted from me he could not get, he thought that there was no need to be with me and he disappeared. (Sarah, female student with albinism- LSES).

Sarah's story suggests patriarchal sexual exploitation. It can also imply what Morley (2011) refers to as men's construction of women's sexuality as a commodity and as barter trade. Here Morley (2011) talks about how HE female students' sexuality in some universities in Ghana and Tanzania was being used in exchange for good grades. In Sarah's case, her sexuality was used as a commodity for investment. This kind of misogynistic exploitation, as observed, has inflicted a long-lasting grief on Sarah, as she felt vulnerable and betrayed. It haunted her, often reminding her of the brutal killings of people with albinism that were particularly widespread in 2008. The fact of being haunted by the brutal killings is not healthy as it creates an atmosphere in which a student can feel threatened and worried about their personal safety, affecting their capacity to concentrate on her HE studies. Again the construction of women's sexuality as an exchange product, according to Morley, 'produces negative female learner identities' (2011: 113).

Sarah's experience of being sexually exploited and abused is supported by other studies showing that women with albinism are often exploited (Allen, 2010; Mulemi and Ndolo, 2014). In Tanzania, in a study on the lives of people with albinism, Mulemi and Ndolo (2014) reveal that some men were sexually exploiting or seducing women with albinism because of their curiosity to explore whether women with the condition were sexually the same as those without albinism. Likewise a research in Uganda, for example, Allen (2010) found that while people with albinism were often stigmatised and avoided women with albinism were often sexually exploited and abused by men, and that the exploitation and abuse was because of some men's curiosity to feel the difference. A French feminist philosopher, sociologist and psychoanalyst, Irigaray (2004 [1984]) points to curiosity as what prompts some men's desires for sexual relationships with certain women.

Another participant who reflects upon sexual harassment was Angel. Angel emotionally discusses the sexual harassment she encountered from two adult men during her secondary education, when she was fifteen years old. She narrates how the two men tried to take advantage of her financial situation to abuse her sexually. While one of them claimed that he would pay for her school fees the other claimed that he would find people to sponsor her secondary education. In tears and showing signs of vulnerability and humiliation, Angel says:

(w)hen I was in high school, my aunty had a male friend who was living in [the region where her school was], so my aunty asked me to go and collect my school fees from him and she also asked me to contact the man regularly so that he could connect me with people who could sponsor my education. Surprisingly, when I contacted him regularly and when we were close he wanted me to have an intimate relationship with him and he was an adult of around 48 years so I had to avoid him without telling anybody. (Angel, female student with albinism- LSES).

Here, Angel provides an example of her experience of the sexual oppression of young girls. In Angel's case, the 48-year-old man used his economic power to harass her because of her lack of resources. A review study of sexual relationships among young people in the Global South, including Tanzania, conducted by Brown et al (2001), revealed that schoolgirls as young as 13 years old were found to be involved in sexual relationships with older men because they lacked sufficient financial support from their parents to meet their essential school needs. This kind of exploitation illustrates the unequal distribution of power based on gender. It could also be what Morley (2011) refers to as women's sexuality being constructed as an object of barter. While the trading that Morley (2011) talks about was the trading of women's sexuality for academic grades, in Angel's case it was the trading of her sexuality for financial favours, which, as revealed by Brown et al (2001), some young girls sometimes opt for as a way of enabling them to interact with educational opportunities.

Some girls exploited in this way can become pregnant. Osler and Vincent (2003) inform us that pregnancy in schools can sometimes mean the end of girls' participation in formal education. They suggest that it can end young girls' dreams, even for those who are highly-motivated and committed to education. This is because the motivated girls may encounter barriers in progressing with their education due to social perceptions and treatment, and the risks involved. In this context, not only was Angel at risk of unplanned

pregnancy, but also of sexually transmitted diseases, which have a damaging impact on learning and well-being. Given that Angel's financial ability was limited, the chances of being manipulated were high. This was because poverty, and lack of school fees, food, transport and shelter were reported as among the factors that led schoolgirls in Tanzania to be sexually abused and consequently become pregnant (Legal and Human Right Centre (LHRC), 2011; Lugongo, 2010).

Worldwide, adolescent pregnancy affects the learning process of many girls. In Tanzania, adolescent pregnancy is one of the factors that has been associated with dropping out of school among young girls (MOEVT, 2010; LHRC, 2011). According to a report released by the Tanzania Media Women's Association (TAMWA) (2011), in the period between 2004 and 2008 approximately 28,590 young women in Tanzania dropped out of school due to pregnancy. Out of these, 11,599 girls were secondary school students and 16,991 were primary school girls. Further statistics released by MOEVT (2008) reveal that every year approximately 8,000 adolescent girls in Tanzania drop out of school because of pregnancy. Haki Elimu's (2011) report indicates that from 2003 to 2010, approximately 50,000 schoolgirls dropped out of school due to pregnancy, most of whom did not return to school to continue with their studies.

Adolescent pregnancy does not only affect the educational dreams of girl children like Angel but can also result in social problems such as being removed from home, or being shamed and stigmatised by the surrounding community. Adolescent pregnancy is also a health risk for young girls. According to Loaiza and Liang (2013) in some African countries adolescent pregnancy was recorded as a major cause of deaths among young women due to suicide or abortions carried out by non-professional medical personnel. The sexual oppression that Angel implies can be a barrier to young women as it impedes their opportunities to education and has major implications for the HE participation of women like Angel. Omale (2002 cited in Morley, 2011: 102), in his study in Kenya, found that sexual harassment was a major factor deterring women from participation in HE.

Another participant who implies the sexual harassment of women is Loveness, who relates how she was intimidated and provoked. When talking about her university experience and barriers to HE participation, Loveness discusses an incident when she was walking within her university surroundings and heard a male voice calling her. She says that because of

her poor vision - especially when she was walking in the sun- she could not see the person who was calling her or from which direction he was calling. So she continued walking and went where she had planned to go. Loveness says that she later realised that the person who had called her was a male teaching staff when subsequently:

(h)e entered the class and saw me sitting in the front desk and told me to get out of the class. I cannot think anybody can frustrate somebody like that. I cannot imagine somebody in his right mind can do something like that. Other students and teachers saw what that teacher did to me. This in one way or another affected me because I had to go home. (Loveness, female student with albinism- MSES).

Loveness' expression indicated that she was provoked and terrified into leaving the unsafe university premises. This could therefore mean that the teacher had harassed Loveness to prove that as a man he cannot be ignored or rejected by a woman, thus creating fear not only in Loveness but also in other students in the class, particularly women. We are told that this kind of harassment against women is spreading widely in some HE institutions, affecting women's learning (Molla and Cuthbert, 2014; Morley et al., 2011; Morley et al., 2006; Britwun and Anokye, 2006; Omale, 2002; Simelane, 2001; Chan et al., 1999). These findings can imply misogyny and at the same time that women including women with albinism do not belong in HE (Ahmed, 2004a; 2012).

David gives an example of gender-based harassment similar to that of Loveness. It involved a woman student with albinism (pseudonym Martha) and a male teaching staff at a university where David was studying. The male teaching staff rudely destroyed Martha's examination paper after she had complained about the size of the font. David says when Martha asked for another examination paper because the one presented to her was in small fonts and she could not read it clearly:

(t)he lecturer replied 'how come you have glasses' and then said nasty words to the student. So that student lost control and went out of the examination room crying. When the student left the room the male lecturer considered it as a lack of respect so he destroyed her examination paper and said 'we will meet in the department'. (David, male graduate with albinism- LSES).

Greer (1999) suggests that aggressive men sometimes interpret women's speaking as provocative. The aggressiveness that David implies can sometimes be activated when men feel their superiority had been provoked. In patriarchal cultures like those in Tanzania, the male teaching staff was expected to be strong and aggressive while Martha was expected

to be silent and subservient, so in cases where Martha demanded her right to have an examination paper with an enlarged font she was considered provocative; therefore, she needed to be controlled and retained in her silent and subservient position. The male teaching staff's aggression did not only make Martha feel vulnerable and weak but it also affected her learning mood, which was likely to affect her academic performance. It is also possible that in some instances the male teaching staff's aggressiveness could cause antagonising relationships between him and Martha because, as Sarah says:

(a)t the end of the day he told me you will fail, and I failed that course. (Sarah, female student with albinism- LSES).

While what Sarah talks about can imply that as a woman her cognitive capacity is limited and therefore she is not capable of passing her HE examinations, there are also signs of a victimisation which results from the weaknesses in the assessment system. The study by Morley et al (2010) noted similar weaknesses in the assessment systems of some universities in Tanzania. They felt that assessment was not adequately regulated as individual teaching staff could grant and amend academic grades as they pleased. Such loopholes in the system give way to favouritism or victimisation such as we have observed in Sarah's case. This kind of assessment system is very risky for the participation and successful completion of students, particularly women. In Ethiopian universities there were cases reported of female students having been sexually propositioned by teaching staff and being victimised and given low grades when they rejected these advances (Molla and Cuthbert, 2014). Therefore, the victimisation that Sarah talks about can be harmful to her HE success. It is harmful because the fail that Sarah received will be a permanent stain on her academic records. The stain can often haunt her, particularly when she has to compete for merit-based employment for possible economic and social success.

Happiness also talks about the harassment that she received from a male teaching staff during her university education. Her poor vision meant that she frequently had to go close to the board to read what the teaching staff had written so:

(t)he lecturer said I have to go with you to your organisation because I know you are very naughty, you don't have poor vision. You can see but you are pretending so that you can get special favours. (Happiness, female graduate with albinism- LSES)

Happiness talks about being objectified as deviant and fraudulent. This could imply that as a woman she was dwelling in spaces that already had prescribed ways of moving

(Ahmed, 2000). It seems that the male teaching staff already had assumptions as to how Happiness, as a woman, should behave; therefore when she behaved contrary to his expectations she was constructed as being naughty or deviant. This was because she was seen as having moved out of her prescribed space. The objectification of Happiness as naughty or deviant can restrict her freedom of expression and make her develop fears of talking or speaking in public spaces, thus impeding her participation in class discussions or activities such as study trips.

Happiness also talks about another accusation made by the same male teaching staff against her. She says that he accused her of being a liar and pretending to have poor vision because she needed a special favour. Here Happiness articulates de Beauvoir's (2011[1949]) argument, made six decades ago, that in the process of objectifying women, men often claim that women are not capable of doing independent work. De Beauvoir ((1949[2011]) also says that sometimes men can limit women's independence so as to sustain their dominance and superiority over women. The accusations of incapability made against Happiness can be the male teaching staff's tactics of keeping her dependent on men so that they could easily exercise their control over her. On the other hand, they may be what Ahmed (2004a) sees as anxiety over loss of control, which I have discussed in detail in Chapter Four. Here, the loss of control would be for the HE space that men often occupy.

While Angel, David, Sarah and Happiness reflect upon the harassment by teaching staff, Elizabeth, a female member of the teaching staff, talks about students' harassment of a female student with albinism (pseudonym, Judith). She says:

(w)e had a student with albinism who killed herself and it was because of stigmatisation. She had a boyfriend and her boyfriend decided to ditch her, if I can say that, and so she didn't want that and she took her life. (Elizabeth, female teaching staff).

Elizabeth is giving an example about women's resistance of misogyny and patriarchy. Rich (1980) says women can say no to patriarchy in an act of resistance. She says the resistance requires role-playing, which can be self-hatred, breakdown, alcoholism, suicide or intra-woman violence. Judith resisted patriarchy with her own life. Joel, a male government official I interviewed in this study, was a student at the university when Judith committed suicide. Joel recalls the tragic incident and says that Judith committed suicide

after her boyfriend decided to break up with her because his friends and other students were laughing and bullying him for having a girlfriend with albinism who in Ahmed's (2004a) terms is seen as a stranger or an intruder in HE, as discussed in Chapter Four.

While Ester and Abraham, who are NGO officials, were also aware of Judith's suicide and blamed the lack of counselling services, Loveness, a student with albinism, talks about a similar experience to that of Judith. She talks about the laughing and bullying that her boyfriend faced before they had to break up. Loveness painfully talks about how her boyfriend's friends and other people she did not even know would objectify her by making humiliating comments on Facebook about her relationship with her boyfriend. She says:

(i)t was painful, but I had to concentrate on my studies and my goals and forget all the bad words that people were saying about our relationship. (Loveness, female student with albinism- MSES).

Using her own experience Loveness provides us with an example of online violence against women. The Internet can sometimes become a ground for practising misogyny. For example, Bates (2013) in her blog 'The Everyday Sexism Project' has been reporting how online violence against women and girls is widespread, and indicates how even girls as young as ten have been molested and abused online. This is, therefore, a new way of locating women at a lower position and limiting their access to power. The experiences of Loveness, Angel, Sarah and Happiness, who I interviewed, as well as those of Martha and Judith who were reflected upon by David and Elizabeth respectively, are examples of the experiences of women in HE. Their experiences provide an answer to the specific HE academic experiences of female students with albinism in terms of teaching and learning, assessment and learning support, thus answering my fifth sub-question.

Misogynistic elements reflected upon by Loveness, Happiness, David, Sarah and Elizabeth do not only apply to women with albinism in HE but also to other women students. Since university education was introduced in Tanzania, its structure has displayed misogynistic tendencies as the structure has remained predominantly male (TCU, 2013). For example, of the first students to be enrolled at the first HE institution in Tanzania, the then Dar es Salaam University college which is now the University of Dar es Salaam (also see section 1.8), only one of the fourteen students was a woman. Even after the college became a

fully-fledged university in 1970, the number of women continued to be low, at only 13 per cent (Sanyal & Kinunda, 1977). In Tanzania, even in recent years, women in universities still account for only 36.2 per cent of students (see section 2.2). This gender order, in my opinion, has been taken to be a natural way of being (Leathwood & Read, 2009). Thus, any increase of women in HE participation is likely to be taken as a threat to the natural gender order as it reverses that order. According to Greer (1999), men can sometimes be aggressive when they believe that their privileged positions have been threatened (see this section above). The threat to the reversing of the gender order is therefore likely to receive some hostility.

In recent years, the numbers of female students in HE have increased. In some countries, such as those in the Global North, female students in HE have outnumbered male. When women in HE outnumber men, Leathwood and Read (2009) say that there can be a fear of feminising HE. According to Leathwood and Read (2009), the feminisation of HE rests on the assumption that women are basically taking over the sub-sector. This means men are losing their domination space or power, and thus women are taking over men's dominant position. The fear of feminising HE can imply misogyny, as women are seen as not worthy of occupying HE territorial spaces which had basically belonged to and been held by men for a number of years.

Women can be seen as not worthy because as mentioned elsewhere, they are often seen as ungovernable, helpless, dependent, weak and vulnerable (de Beauvoir, 2011[1949]; Holland & Ramazanoglu, 2002). Thus, the perceived notion that HE is being feminised can mean that there are negative elements in women about which universities should be warned. It can also mean that women are invading territories meant for men. The negative perceptions about women can mean that not only did women with albinism experience misogyny but so did other women in HE. However, women with albinism, even those in HE, of course have a unique experience, being faced with superstitious beliefs that they are a cure for HIV/AIDS. Such beliefs can more easily see them subjected to rape or sexual advances (see Philemon's quotation in section 4.1) than those without albinism.

5.5 Summary

When the data of this thesis were compiled and condensed, one of the themes which kept emerging from the experiences of all 20 participants in this study was misogyny. This meant that to understand the interaction of students with albinism in HE, misogyny as a phenomenon had to be theorised. This chapter therefore focused on misogyny, that is, the hate, blame, harassment, abuse and gender violence which women with albinism, as well as mothers of children with albinism, often encountered. The key findings are summarised below.

Misogyny, or the hating of women, has existed and been practised for centuries, as shown by various religions and philosophical literatures. The existence of misogynistic elements in religious and philosophical writings has influenced various cultures and systems. Misogyny has therefore been legitimised, normalised and structured in cultures, practices and systems such as education systems, including HE. In this context, despite various interventions such as widening participation strategies to include women in Tanzanian HE, the sub-sector has remained the domain of men, and women have often been seen as outsiders who do not belong (Ahmed 2004a). When women like those in this research entered HE they were therefore seen as a threat. Some men struggled to maintain their privileged positions and thus some male teaching staff were aggressive to Happiness, Sarah and Loveness so as to defend their superior positions within HE. Given such struggles and defence of space by some male teaching staff, the number of women progressing to HE has been limited, particularly in SSA. Even where the number of women is high, as in the Global North, misogyny has limited them to programmes which have less value in the job markets (Morley, 2006; Grenz et al., 2008).

The aggressiveness exercised by some male teaching staff also carried the message that women like Sarah, Happiness, Loveness and other women with albinism in this research who had entered HE were in the wrong place firstly because, as women, their place was in the private sphere. They were therefore reminded where they belonged, as women, and how they should behave in public spaces. Secondly, they were reminded that, as women, they did not deserve the status that goes with HE because they were expected to be in jobs which did not require HE qualifications and were therefore unnecessarily occupying male spaces.

As women are sometimes seen as unnecessarily occupying male HE spaces, there were some indications that efforts are sometimes made to control women's learning in all phases of education. It seemed that women are controlled through rapes, bullying, harassment and abuse from fellow students, teaching staff and even members of the wider society, as we have seen in the cases of Angel, who was exploited at a young age by a much older man; of Sarah, who was exploited by a married man after she had given birth; and of Judith, who was so bullied that she committed suicide to resist patriarchal control (Rich, 1980). These cases are an indication that misogyny impacts on the education of women with albinism. Likewise, there are indications that misogyny has subjected women to poverty, which has consequently limited their ability to support their children's education, particularly when they are abandoned for giving birth to a child with albinism. In this case, misogyny does not only constrain the education of women with albinism but also that of males with albinism through their mothers, as we have seen in the case of David and the other male students who were reflected upon by Ester and other NGO officials.

The following chapter addresses structures and agencies. It builds on the discussions in this chapter by analysing the factors that have acted as barriers and enablers in the interaction of students with albinism with HE opportunities.

Chapter Six

The Social Reality of Albinism: The Link Between Social Structures and Agency

6.1 Introduction

Social structures and agency are two elements of social reality, which have been debated in sociology for more than 100 years. One such debate is that of Emile Durkheim's (1938 [1895]) theory of social facts, which, according to Sztompka (1994), was dominant in the sociological perspectives of the 1960s. In his theory of social facts, Durkheim emphasised the power of society as he saw an individual as being shaped by society. This view of socialisation made an individual the product of society, thus it downgraded human agency and gave primacy to society, or, in other words, structure. In the early 1970s some scholars began to critique Durkheim's notion of socialisation and focused on Max Weber's views of society. Weber's (1922) sociological theory emphasised individual actions and saw such actions as existing above social forces. Weberian views gave primacy to individual action (agency) and in doing so downplayed the power of society (structure).

The debate about social structures and agency has caused the definitions of both terms to be ambiguous. For example, Bernardi et al. (2007) argue that the only feature that sociologists who deal with social structure often share is their acknowledgement of how hard it is to define social structures. Merton (1976) found that the ambiguities that surround the term 'social structure' derive from the various ancestral lines of sociological thought as such lines were often different in substance and in methods. According to Bernardi et al. (2007) and Lopez and Scott (2000), the historical lines of sociology have influenced a longstanding coexistence of two different conceptions of social structures. They name the first view as 'institutional or cultural structures' and the second as 'relational or positional social structures'.

The two views of social structures, according to Bernardi et al. (2007), can be differentiated by the way they define which elements of society most condition human social action. Institutional or cultural structural theorists see social practices in the form of norms, beliefs and values as the elements which most condition human action. Thus theorists

with institutional or cultural perspectives define social structures as ‘a set of cultural and normative models that define actors’ expectations about behaviour’ (Bernardi et al., 2007: 163). According to Bernardi et al. (2007), scholars with relational perspectives of social structure consider social relations to be the most conditioning elements of human action. These theorists therefore focus on elements that connect individuals, groups, organisations, communities and societies, and define social structure as ‘a system of relation between class positions’ (Bernardi et al., 2007: 164).

Like social structures, there are a number of different definitions of agency. McNay defines agency as ‘the capacity for autonomous action in the face of often-overwhelming cultural sanctions and structural inequalities’ (2000: 10). Sen, an Indian economist, refers to agency as ‘what a person is free to do and achieve in pursuit of whatever goals a person regards as important’ (1985: 206). In the same context, Kabeer, also an economist, describes the term agency as related to the ability of an individual to set his or her own goals and act upon them (1999: 438). Emirbayer and Mische give another definition of agency. For them, agency is ‘the capacity of actors to critically shape actors’ responsiveness to problematic situations’ (1998: 971). The variation in the definitions of structure and agency means that social theorists are yet to agree on a common definition of what structure or agency is, thus making the debates on the two aspects of social life ongoing.

In contemporary debates on structures and agency, some theories link the two elements of social life. Among such theories is Giddens’ (1984) theory of structuration, which sees structures and agency as inseparable, thus as two sides of the same coin. The primary argument in structuration theory is the conceptualisation of the duality of structure and agency (Callinicos, 2006; King, 2006). In this sense, Giddens believes that the repetition of acts of individual agents is what reproduces structures such as traditions, institutions or established ways of doing things. For Giddens (1984), social life cannot be understood by separating human activities or social structures, as they are in relationship with each other and thus emphasise social forces and practices. Giddens (1984) sees that far from structure impinging upon people, it is agency which brings people into play by instantiating them, because he believes peoples’ actions depend upon their perceptions as to the resources they have to access and also on their subjective conceptions of the rules which they often hold.

Archer (1988, 1995, 2000), a British sociologist is another contemporary theorist whose work theorises structures and agency, what is basically the link between micro and macro phenomena. Archer defines social structures as ‘sets of properties and powers that belong to the parts of society and agency as those that belong to people’ (2000: 1). She believes that societies possess emergent socio-cultural properties such as systems, norms, beliefs and values and that humans possess personal emergent properties (PEPs), which are knowledge, self-consciousness and reflexivity. She thus believes that both structure and agency are causally significant elements in social life and therefore in understanding social life none of them should be reduced.

For Archer (2000) structure and agency are two separate entities, which constantly interact with and influence each other. She suggests an analytical dualism approach, which means that the structural, cultural and agential components are analysed separately, implying that none of the components is reducible because each has causal properties and powers of its own which operate in different time-frames. In this context, Archer (1988; 1995; 2000) argues for a morphogenesis theory, which she has borrowed from biological sciences. In biology, the term ‘morphogenesis’ means a process that causes an organism to develop its shape in which the shape emerges from the environment. In Archer’s (1995; 2000) thought, the term ‘morphogenesis’ refers to changes in the shape of things, where *morpho* refers to shape and *genesis* to change of structure, agency or culture. In Archer’s (1995) work, morphogenesis theory is a process that describes how human beings both shape society and are shaped by it.

When we analyse the experiences of students with albinism facing various constraints in interacting with HE opportunities, we cannot look at structures alone or agency alone; we need to look at both aspects of social life so that we can understand their participation in HE better. Archer’s (1988; 1995; 2000) notion of structures and agency and her concept of reflexivity provide a better explanation, as they relate well with my main theory, namely Ahmed’s (2000; 2004a; 2012) wider theory of difference and her notions of strangers and affective economies. In this context, Archer’s (1998; 2003) notion of reflexivity plays a significant part in providing this thesis with explanations as to how the 14 students with albinism constituted their personal power or agency to operate within a world that constructed them as what Ahmed (2000; 2004a) terms as strangers, intruders or not belonging; and how they consequently entered HE. Here, Archer’s (2000; 2003)

progressive specification of course of action is very useful in understanding or explaining how the 14 students with the condition overcame the constraints to become HE students. In her progressive specification of course of action, Archer (2000; 2003) suggests that human beings often have concerns which help them to formulate projects which involve an end result that is desired. It is through these courses of actions that I attempt to explain how and why the students with albinism whom I interviewed were able to interact with HE opportunities despite the socio-cultural constraints on them. Archer's (1995; 2000; 2003) notion of structure and agency allowed me to separately analyse the social and cultural structures in the lives of students with the condition, as analysed in Chapters Four and Five, while her notion of reflexivity made it possible for me to link those structural constraints with students with albinism's agency in order to explain their participation in HE.

Central to Archer's (1995; 2000; 2003) theory of morphogenesis is her notion of reflexivity where human interactions occur within the social setting. In the context of my study, these interactions are those that take place within the social, economic and education setting for people with albinism. These interactions are between the 14 students with albinism and society, economic resources, teachers, fellow students and significant others. In such interactions, according to Archer (1996), structure and culture come together to impact on our actions. This chapter therefore focuses on the interrelationship of structure, culture and agency and analyses the constraints and enablers in the life experiences of the 14 students with albinism in their interaction with HE opportunities. In so doing, it analyses the ways in which structure and culture condition the agency of the 14 students with the condition. In this context, I analyse nuanced or not easily observable structural and cultural conditions that have causal powers to constrain or produce effects on the agency of the 14 students with albinism.

In her notion of reflexivity, Archer (2000) talks about an autonomous internal conversations that a person often engages in. Thus defines it as 'talks that all normal people have with themselves within their own heads usually silently and usually from an early age' (Archer, 2007: 2). For Archer (2000), internal conversations are an individual's personal properties, where individuals consider themselves in relation to their social world and vice versa. Thus internal conversations are only experienced and known by the respective individual and of which the social environment is usually unaware. She gives examples of

such properties as thoughts, emotions, feelings, memories, desires, processes and various experiences that human beings often use to decide about themselves and society. She argues that these conversations continuously run commentaries with natural, practical and social events that often go on in the very person's life. Internal conversations, she believes are widely powered by personal emotions, which are relational to peoples' three types of inescapable concerns. The three concerns are: concerns for one's physical wellbeing, performative competency, and one's self worth. These concerns, Archer (2000) suggests are not only the bases for people to embark on their life projects but they also shape their behaviours and actions. The 14 students talk about their concerns, among them the three types of inescapable concerns that Archer (2000) talks about. They mention their concerns about winning respect, being economically independent, and assisting or changing their students with albinism community. From such concerns, the students formulated projects of becoming HE students so as to overcome discrimination and mistreatment. For example, Meshack says: 'my aim was to go to university so that I can gain respect', while Happiness says her aim was to 'show that people with albinism are valuable', Lucas says 'I did not want to be a burden to my family' and Isaack says:

(i)t was a prestige for someone to enter a higher learning institution and one felt proud. Especially those who attended government university, specifically the [the name of university] to the extent that when you entered a bus and told the driver that you are going to university, he felt like getting out of the way and allowing you to pass (Isaack, male graduate with albinism- LSES).

Isaack implies symbolic power. Given the discrimination that people with albinism often experience, what matters most to Isaack is symbolic power rather than material goods, which are often associated with HE. There are different theories as to the benefits of HE; for example, the economic theories regarding the rate of return or value in the labour market or graduate premium and so on. Then there are the wider benefits of HE in terms of citizenship, tolerance, identity and others. But Isaack's interest is in the identity offered by HE that can mitigate the negativity connected with albinism rather than only economic gains, and thus he rejects a *homo economicus* identity. A *homo economicus*, according to Archer (2000), is an individual who engages agency for purposes of maximising profit due to preferences for money and goods.

Archer (2007) critiques the notion of *homo economicus* identities because she believes human beings often have a multitude of concerns and recognises that this can sometimes

cause a dilemma in our life. She asserts that we can resolve such dilemmas by achieving a *modus vivendi*, which according to her, is the way in which we go about our being in the world. We can handle a multitude of concerns as our *modus vivendi* enables us to decide on our ultimate concerns, which are the things that matter to us most and are our long-term goals.

Although the 14 students with albinism participants have a multitude of concerns, my focus is on their ultimate concerns, and life projects, as stipulated above. In this context, I focus my analysis on the three sub-themes that emerged from the students' experiences of overcoming their concerns and achieving their life projects. These sub-themes are socio-economic positions, teaching practices, and teaching and learning material and the learning environment.

6.2 Socio-economic positions and life chances

Archer (2000) says that at birth we are immediately assigned a position of belonging to a particular collectivity or system of social stratification. In this way, we either have privileges of the collectivity or lack them. Such positions, according to Archer, are agential properties that people acquire involuntarily. In Tanzania, the latest household budget survey shows that approximately 85% of the Tanzanian population, that is, 39 million people, live in poverty (World Development Report, 2011). This means that about 39 million people in Tanzania lack socio-economic privileges. Archer (2000) sees such people as primary agents who share the same life chances in the distribution of world resources. She sees them as having no agential power in society, except for their implicit grouped effect that they exercise as demographic power simply through the virtue of their large numbers.

As mentioned in my introduction, in Tanzania we often consider the parents' education and employment status to determine a student's economic status. Going by this classification, I would say that only John, Loveness and Lucas, who had parents who had completed HE, could be categorised as middle-class students. As mentioned in the previous chapter, John had a mother with HE qualifications whereas Lucas and Loveness had fathers with HE degrees. The rest of the 14 students with albinism participants were first-generation HE students.

First generation HE students are defined as those for whom ‘neither parent has had access to a university education and completed a degree’ (Thomas and Quinn 2006: 50). It is less common for students whose parents do not have HE, particularly in developing countries like Tanzania, to choose HE because they often lack guidance or knowledge about it from within the family circles. This means they lack role models to prompt their aspirations. However, Morley et al. (2010) reveal that in Tanzania, other family members like aunts or uncles and also members of the wider community can be role models to first-generation HE students, and thus prompt aspirations towards HE. In the same spirit, the 11 students with albinism who were first-generation HE students say they were inspired by their uncles, teachers, friends or fellow students. However, these students say that their actions towards entering HE were taken independently. David, for example, says he was inspired by his uncle to undertake HE, but his action of seeking information and applying for HE was made independently. As for Grace, she says her teachers inspired her but she undertook the admission process on her own. Likewise, Happiness says:

(I) began to be inspired to undertake HE during my O level education. Here, when the results were released and I heard someone has passed to go for high school I would be jealous and I would say to myself I also want to go to high school. Why shouldn't I go to Form five? I would ask myself. (Happiness, female graduate with albinism- LSES).

Happiness is a first-generation HE student, and therefore had no role model to prompt her aspiration. Nevertheless, she was having an internal conversation which showed that although her desire for HE was influenced by other students, the external world had no direct influence on her choice to embark on it. This may mean that in formulating the intention to become a HE student, Happiness, and probably the other 11 students with albinism who were first-generation HE students, were engaged in what Archer (2003) refers to as an autonomous reflexivity mode of decision-making. Archer (2003) believes that autonomous reflexivity is often present in actors who are able to internalise their conversation and formulate their life projects independently. Although Happiness and the 11 students with the condition were subject to external influence in their desire for HE, they decided on and took action to enter the sub-sector of their own accord, illustrating an autonomous decision in making their life choices.

While 11 students with albinism in this study might be considered to have engaged in autonomous reflexivity, John, Loveness and Lucas seem to have engaged in a

communicative mode of decision-making in their HE choices. According to Archer (2003), actors using the communicative mode of decision-making tend to externalise their internal conversation and rely on their significant others for their actions. The three participants, Loveness, John and Lucas, seem to have engaged in a communicative mode because they have parents with HE backgrounds who thus have knowledge about the sub-sector and may have influenced or guided their decisions.

John, for example, talks about his discussions with his mother and siblings regarding the admission process and his choice of a programme in light of his low vision. Lucas, whose father and siblings have HE qualifications, also talks about their discussions and how his brother, who is a scientist, wanted him to enrol in science-related programmes but he could not take such programmes because of his low vision. Likewise, Loveness, whose father is a HE graduate, talks about having discussions with both her father and mother about her HE career in a health-related programme. She even says that she had to consult her relative to establish if other people with albinism had taken the programme to which she aspired. The discussions that the three students with albinism had with various people thus externalised their internal conversations, making their decisions communicative and having support from parents. The communicative interaction that students like Loveness, John and Lucas had with their parents enabled them to easily interact with HE opportunities. Such interaction is thus one of the means of support enabling students with albinism to enter HE.

Another mode of decision-making that was observed in almost all the 14 students with albinism participants is meta-reflexivity. Archer (2003) relates this mode of decision-making to those actors who are dominated by thoughts or life purposes that focus on assisting others. The 14 students with the condition in this study point to one of their reasons for choosing HE as being so that they can assist their fellow people with albinism to acquire a respectable and high-quality life. This means that the wish for recognition and inclusion was what had prompted the 14 students with albinism to achieve their goal of becoming HE students. For example, David says that given the negative perceptions that some people had about people with albinism, he undertook HE so that he could be a good example to other people with albinism and consequently change negative perceptions of albinism. Grace, Loveness, Thomas, Sarah, and John all say they wanted to establish organisations which would support those with albinism. These five participants, who were

interviewed separately, say they envisaged institutions which would focus on supporting the education, welfare and financial needs of people with albinism. The desire expressed by Deborah, Meshack, Simon, Isaack, Angel, Lucas and Peter was to support people with special needs, particularly people with albinism. As for Happiness, she says:

(w)hen I was a child, I would wish that one day I would be able to defend people who are discriminated against. I do not only refer to people with albinism but all people who are in the minority. (Happiness, female graduate with albinism- LSES)

Happiness and the 13 students with albinism portray signs of meta-reflexivity in their decision to undertake HE. Archer (2007) suggests that people drawing upon the meta-reflexivity mode in making decisions were increasing globally. The intention of Happiness and the other 13 students with albinism to become HE students because they wanted to help other people supports Archer's (2007) suggestion.

Looking at the socio-economic position of some of the students with albinism, I would say that both Grace's parents have primary education and are peasants in one of the rural areas in Tanzania. In Tanzania, poverty in rural areas is more severe than that in urban regions (Human Development Report, 2011). Most households in rural areas are subsistence farmers with limited access to social services and material goods. Grace was thus born into a social structure put in place by activities of people in the past, now the long-dead (Archer, 1998) and inherited the social structure of lacking privileges from the actions of her ancestors, which means that the poverty structure pre-existed her agency.

Grace therefore started her agential cycle in a situation that resembles what d'Addio (2007) calls intergenerational transmission of disadvantage. Intergenerational disadvantage, according to d'Addio, is a situation in which multiple generations of the same family experience high levels of disadvantage (2007: 11). People confronted with intergenerational disadvantages can sometimes internalise distorted values and accept poverty as part of their lives but for Grace it was different, as she says:

(i)t is because of the hard life that I passed through. That is what motivated me to aspire to HE. My parents are peasants so when you want something you cannot get it. This way, you lack basic needs, not food but basic needs like school uniform, exercise books and something like that. (Grace, female student with albinism- LSES).

Grace's reflection implies a lack of socio-economic capital. It is generally accepted that students with socio-economic capital, on average, perform better than those who lack such capital. This is so because those with such capital have better learning environments and facilities, and the advantage of parents' knowledge about educational matters, including HE, which make them seen as being responsible towards the education of their children. For Grace this is not the case; she lacks such capital and advantages but she is a bright young woman whose academic performance has been exceptional in all stages of her education.

Grace's case could be seen as one where human agency is in play to overcome what Archer (2000) described as life chances at birth. But Grace says she had the support of her teachers, who encouraged and motivated her to work hard. Thus she worked her way to HE. Here she mediated the structure of lack of resources and transformed the morphostatic cycle of the outcomes of life chances (Archer, 1999). In this way she transformed the structure that transmits intergenerational disadvantage after excelling academically, and went on to enter HE. Interestingly, she also influenced her younger sibling to enter HE, thus transforming her family morphogenesis cycle, an example of the multiplier effect found in the study by Morley et al. (2010) on WPHEGT.

Sarah is another participant who reflects upon socio-economic factors in her interaction with HE opportunities. As mentioned in Chapter Five, Sarah was brought up by her mother and grandmother after her father rejected her at birth, thus growing up in a structural FHH that is often linked with lack of opportunities (Chant, 2006). Archer (1990; 1998) sees poverty within FHH as the consequence of past actions of the long-dead, which cannot easily be changed in the short term by individuals. Thus the poverty of Sarah's grandmother or mother cannot be blamed on them but on the actions of patriarchy, which denied them better education and employment opportunities.

Like that of Grace, Sarah's morphogenesis cycle also started in a structure that pre-existed her agency. In this context, Sarah entered a world that had been deeply structured and culturally conditioned by prior oppressive actions of patriarchy. She entered a world where the expected benefits of education differ according to gender, with more households favouring the schooling of their male children than that of girls. She also entered a world where the loss of a girl's domestic labour is far more felt than that of a male child,

depriving women such as her mother and grandmother of the right to continue school beyond primary education. In this way, Sarah encountered a morphostatic structural cycle where emotions of hate and fear of albinism circulate and where her mother had primary education and is unemployed, and her grandmother is employed but in a junior, low-paying position, which can be termed as a feminised poverty household (Chant, 2006; Pearce, 1978). Sarah therefore involuntarily confronts an emotional and a misogynistic structure and culture, as detailed in Chapters Four and Five, which consequently affected her smooth transition to HE.

It is agreed that feminised poverty widely impacts on agency but Sarah has been able to work out a course of action to mediate this structure. Having failed to obtain the required grades in her 'O' level examinations in order to continue with her 'A' level education, Sarah chose to re-sit the same examinations by attending tuition classes. In the course of re-sitting she says:

(i)f I got the Tshs 15,000/-, I would attend my tuition classes but if I didn't I would stay at home and do my own studying. (Sarah, female student with albinism- LSES).

The amount that Sarah was required to pay per month as tuition fees is approximately £6. Archer (2000) suggests that when we judge actions, we should not only analyse the expectation of the agents' concerns but we should also measure the value being applied. In this context, when I measure the value that Sarah applies to interact with HE opportunities, I can observe the aspirations in achieving what she cared about most given that:

(t)he first university to attend was [name of university] in [name of region]. I was selected to do a [name of programme] degree. So I applied for a loan and I got 100 per cent. I began my study there but later they raised the tuition fees. When the fees were raised I had no one to pay for me. Considering the problems we had at home I could not continue. That fee, nobody could pay it so I found myself having to be at home for one year (Sarah, female student with albinism- LSES).

Given the feminised poverty that structures Sarah's life she could not continue with the first university. This led to the interruption of her HE project as she stayed at home for a year. Archer (2000) pinpoints that sometimes when our projects are interrupted we can have internal conversations, where we might question ourselves as to whether the projects are worthwhile, whether they should be continued or whether we still care enough to continue with them. She states that some people do not continue with the projects but emphasises that those who do are the committed ones. Sarah continued with her project;

in this context she can be seen as a strong, committed person who did not give up what she cared about even after she had a baby. By having a baby she engaged her *modus vivendi* and was able to handle the roles of mother and student actor at the same time. On the one hand, Sarah's decision is supported by the autonomous reflexivity, as she was not ready to let go of her self-chosen dream of being a HE student. On the other, Sarah delineates a communicative reflexivity mode of decision-making. Sarah was not totally independent in her endeavour to achieve her life project. She talks about the encouragement from her mother and best friend. As mentioned in Chapter Five, Sarah reflects upon how her mother had to register for 'O' level classes as a private candidate to encourage her to progress to HE. She also talks about how her friend, who was then an HE student, paid her application fees and filled in her application form so as to encourage and push her into proceeding with her project. While such experiences confirm a communicative reflexivity mode in Sarah's life, it could also be that without the financial support of her friend, Sarah could not have participated in the HE application process to qualify for admission and consequently receive the financial support system in place for students like her, indicating the contribution of Sarah's friend in Sarah's participation in HE.

John is another participant who implies socio-economic factors in his experiences. He is from a middle class family by Tanzanian standards and so possesses privileged life chances, as he says:

(I) was 19 years old when I decided that I wanted to do HE. All my family members attended HE, so I felt like it was a norm. (John, male student with albinism- MSES).

Having been brought up in a family with HE experiences, John saw HE as a family culture. According to Reay et al. (2005), to middle class students like John, HE can sometimes be a natural progress and thus not a matter of choice. This could mean that his choice for HE was made on the basis of following the family norm rather than only because of his own interest. Archer asserts that there are individuals who 'act out of their own self-interest' (2000: 75). She refers to such a person as *homo sociologicus*. Garfinkel (1984) says that such individuals often act that way because when they act contrary to the norms, other actors may react negatively to the breaking of normative behaviour. In this context, then, as a way of preventing negative reaction from family members, John might have acquired a *homo sociologicus* identity in an attempt to adhere to the family norms and values, illustrating Ahmed' (2000) view that the unhappiness of others can circulate and make us to do things. John's choice could have been conditioned not

wishing to make his family members unhappy. However, Archer (2003) talks about a *sifting process* by which an individual has powers to decide upon what is a desirable way of life. John may have involved such a *sifting process* in his choice for HE, as he illustrates an autonomous reflexivity, particularly when he talks about his desired way of life. For example, John says ‘I took [name of course] because I always wanted to become a [name of profession].’ Such reflexivity shows his autonomy in deciding upon his desired social role, thus rejecting a *homo sociologicus* identity, although there are indications of family norms and values influencing John’s agency. This could indicate that John was not totally free from family support and influence which were enablers to his HE participation. For example, Eliza, whose children with albinism all entered HE like her, talks about how she encouraged them at every stage of their education by emphasising that the level they had reached was not enough. Loveness, John and Lucas had a similar push by their parents thus, enabling their smooth participation in HE, unlike the 11 student with albinism who were first generation students.

6.3 Being excluded and included

The primary focus in Archer’s (1995) morphogenetic theory is human interactions. These are the interactions that take place between agents in the social space. In the context of this section, these are the interactions between students with albinism and teachers. The interaction between students and teachers is crucial as it has an impact on students’ lives. When teachers enter classrooms they enter the world where they are either constraining or enabling the students. In relation to a student’s education morphogenesis cycle, the teacher-student interaction is the first stage in which a student interrelates with structural and cultural conditioning. In this context, teachers have a key role to play in constraining or enabling their students’ agency.

Although in Tanzania some teachers enable students, others constrain them. For example, studies in Tanzania reveal that in some cases teaching as a profession is chosen as a fall-back position, that is, when nothing better can be found (Ndunguru, 1976; Malangalila, 1998; Towse et al., 2002; Barret, 2008), or because of the lack of qualifications necessary to enter other professions (Towse et al., 2002; Barret, 2008). Teachers with such mind-sets or low professional skills are likely to produce constraining structures that can impact on students’ agency.

The 14 students with albinism in this study reflect upon their experiences with their teachers in various ways. Although they talk differently about their primary, secondary and HE teachers, the common issue discussed is the academic experiences in terms of teaching styles. The students see teaching as either a constraint or an enabler in their agential morphogenesis cycles, and reflect upon a specific teaching practice which they refer to by a metaphor as ‘this plus this equals this.’ Thomas gives an example:

(w)hen some teachers were teaching, for example, mathematics, they would point a stick on the blackboard and say ‘this one plus this one is equal to what?’ So you would hear just a reply from your fellow students saying ‘it is equal to ten.’ But you don’t know which number the teacher had pointed to because you cannot see, so you have to ask someone near you which numbers the teacher had written on the board. (Thomas, male student with albinism- LSES).

Thomas implies teaching deficiency: how some teachers are culturally and structurally trained to teach a certain type of students and thus neglect the students who are different. Likewise, the curriculum could also be structured for certain students. Thomas had to engage his self-consciousness to mediate structural and cultural teaching conditions by asking a student next to him for an explanation. Thus a morphogenesis takes place through a peer support network and Thomas’s agency is enabled. It follows that he passes his primary school examination and moves to the next cycle of his secondary school.

Due to his poor vision, Thomas depended greatly on written notes from his fellow students but in some cases students were reluctant to give him these notes because they needed them for revision. Thomas would then contact the teachers in question and:

(w)hen you go to teachers they would say ‘go back to your fellow students.’ So it is mistreatment because sometimes the examinations are approaching and yet you don’t have any written notes for revision so it is very difficult for you to perform well in your ‘O’ level education (Thomas, male student with albinism- LSES).

Thomas’s experiences with teachers, which does not differ much with Deborah, Lucas and Simon’s experiences are frustrating and also heart-breaking, and can affect their agency. Thus result to the fourth mode of reflexivity, which Archer (2007) refers to a fractured reflexivity. To Archer (2007) this mode occurs to individuals whose internal conversations intensify distress or frustration consequently leading them to damaging course of action. But Archer (2000) says human beings have *pathos* and *logos*, which work together to produce integrity, which prevents a person from becoming schizophrenic when she or

he is pulled in different directions of mistreatments. Yet Matsuda (1993) suggests that victims of hate often experience physiological symptoms and emotional distress. This way, the *pathos* and *logos* that Archer (2000) talks about might not work in people with albinism including those who participated in this research, who have often been victims of hate as elaborated in Chapter Four.

Furthermore, Ester talks about the trauma that is often experienced by children with albinism, thus further rejecting Archer's (2000) notion of *pathos* and *logos*, particularly for victims of hate like Thomas. In contrast, Thomas says:

(o)ne day my mother called me and told me 'your father doesn't want me to invest any more in your education because he wants me to concentrate more on your siblings' education.' This was very painful and from that day I assured my mother that I was going to perform better than other children in the family, and I did. (Thomas, male student with albinism- LSES).

This reflection illustrates Thomas' agentic qualities of fulfilling self-promises. He also confirms Archer's (2000) notion of *pathos* and *logos* as human properties, which often prevent people like those with albinism from being affected by oppressive structural and cultural practices, as he says:

(I) struggled and listened carefully to what the teacher was saying when writing on the board so I became active. Some students who did not understand the teacher would even come to me and ask 'did you understand what the teacher taught us today?' I would say yes, so I would explain to some of my fellow students. Because many students were coming to me for clarification, I would be explaining to them and also listening to their views and here I would be gaining a lot of knowledge. (Thomas, male student with albinism- LSES).

Having a project to accomplish, Thomas takes his destiny in his own hands and engages what Hannah Arendt (1958) sees as a unique potential to do something. Thomas reveals his distinct uniqueness in his ability to listen and memorise which he supplements with his creativity, and develops a strategy to remember and mediate the structure by clarifying and explaining to his fellow students. In this way, as Archer argues 'society cannot be held to shape him' (1995: 289) as despite various social constraints, Thomas was always top in his class examinations. Again, he is the only person in his family of five siblings who passed his 'O' and 'A' level examinations and entered HE. However, Thomas says that when his father and mother passed away and he had passed his examination to enter Form One, he had no one to pay his school fees. He therefore contacted a religious organisation,

which volunteered to support his education until he had completed his 'A' levels. Despite his unique potentials, Thomas admits that he would not have interacted with HE opportunities if it were not for the financial support from the religious organisation. This is a good example of agency. However, there are material implications, for example who has the resources to pay for education. This means that Thomas' creative was not enough to allow his agency without the support from the religious organization.

Human beings, as Archer (2000) pinpoints, are self-aware and also capable of reflecting upon themselves and their environment. Students with albinism are aware of themselves and their learning environment, which consists of constraining teaching styles. This way, Ester, a female official of one of the non-governmental organisations (NGO) which is responsible for the education and welfare of students with the condition in Tanzania, says: (o)ne thing with people with albinism which I have noticed is that they are very good at listening and the brain is taking in all the material they hear, sucking like a sponge. So the most important thing is to talk to them, speak out; they will grab that better than when you are writing on the board for them to copy. (Ester, female NGO official).

The specific identity that Ester talks about with regard to students with albinism could be emerging from their learning environment. The rote learning could therefore be a conscious strategy that students with albinism internalised as an action to mediate constraints in teaching conditions and visual impairment. Sarah, Lucas, Deborah and Happiness confirm Ester's reflection. Here Happiness says:

(w)hen the mathematics teacher would come and would say 'x' minus so and so, I didn't even know what number had been written, I would say this teacher is teasing me. So I would collect my things and go out. So during my 'O' level education I made up my mind that I would deal with only five subjects which I could listen to carefully and understand and I didn't have to see what is on the blackboard. (Happiness, female graduate with albinism- LSES).

While Happiness is talking about her experiences at a secondary phase, which further responds to my sub-question three, she is also talking about adaptation in constraining learning environment. According to Archer (2003), reflexivity is the power that humans often possess which enables their ability to monitor themselves and adapt to different conditions. Having examined how her learning environment impacted on her learning, Happiness decides that her personalised way to overcome the structure was to select five

subjects, illustrating the interplay between her personal identity as a person with poor vision and her social identity as a student actor.

Prior to joining HE, Happiness attended a primary school whose cultural history was that no student had ever passed standard seven examinations to join Form One. As she says:

(I) was asking myself why it was like that. So I said no, in our class we must pass and go to Form One. So we were having a lot of discussions and thank God some of us passed and joined Form One. (Happiness, female graduate with albinism-LSES).

Here Happiness displays her incredibly resourceful and assertive characters in a world where there is no hope. Archer (2003) says that in such a world people often determine their own interest and plan ways they regard appropriate to achieving their ends. Being in a school where there is no hope of succeeding can affect a morphogenesis of agency. But as a strategy to mediate the structure of poor performance, Happiness makes promises to herself when she says ‘we must pass and go to Form one’. Here she chooses discussions with her fellow students to construct what Archer (2000) refers to as a corporate agent, which would enable her to fulfil her promise. Archer (2000) sees a corporate agent as a collectively transformed primary agent. For Archer, a primary agent as mentioned elsewhere is an individual who has no power to change structures. Therefore through the use of discussions Happiness constructs a corporate agency with fellow students. This way, collectively, they changed the structure and for the first time in the history of the school, four students including Happiness were enabled to pass their Standard Seven National Examination and joined Form One. This means that Happiness’ agency was enabled through the promise she made but gathered external support of the collective of students.

When talking about their learning experiences in various phases of their education ladders, three students with albinism reflect upon their vision capacity. Here Happiness, says, ‘in my case I can see something which is in front of me but if it is high I cannot see it; even if I try, I cannot’; Simon says, ‘even if I come closer to the blackboard I cannot see’; and Deborah, who cannot see what is written on the board says:

(s)o what we usually do, for example, myself when I have been in the class maybe from morning until around two in the afternoon when I finish the day’s session, I go to maybe [name], [name] and so on asking for their notes then I write. You can imagine in a day you might have done six subjects from morning till two so

you have to write all those notes, can you imagine the energy that I use to pass my examination. (Deborah, female graduate with albinism- LSES).

Deborah implies how she experiences HE as stressful thus gives examples of extraordinary agency that she possesses, without which she might not have participated in HE. However, she also talks about the support she received from a male middle class sympathiser who assisted her with tuition fees after she had dropped out of HE to be employed in a low-paying job due to financial constraints. Deborah had lost both her parents and she had no one to support her basic and educational needs. Deborah says that a sympathiser in his early 50s, who had seen her efforts and hard work in HE, pulled her out of the low-paying job and volunteered to pay for her education and basic needs when continuing with her university education. It was a matter of chance that a sympathiser enabled Deborah to continue with her university education, given that her university had no systems to support students who were at risk of dropping out. Likewise, the government did not offer any such support apart from the student loan system, which Deborah did not have because she was taking an Arts-related programme which did not qualify for such a loan.

Sarah is another participant who reflects upon her learning experiences in her primary school and teaching styles. Unlike other students with albinism she talks positively about the four teachers in her primary school who were trained to teach students with special needs and recalls how, when she interacted with these four teachers, her school examination results changed drastically. From being almost the last in the class she rose to be number four or five. She attributes her achievement to the teaching styles of these teachers, namely close contact and clear explanations. But Sarah's luck is uncommon in Tanzania. A study by Komba and Nkumbi (2008) on 'Challenges of Teachers in Tanzania' reveals that one of the factors widely mentioned by teachers as a challenge was teaching students with special needs. The challenge, according to Komba and Nkumba (2008), arises from the fact that most teachers do not have the skills to teach students with special needs, so the learning of students with special needs, such as students with albinism, is difficult, especially when there is a lack of support.

6.4 Experiencing an interchangeability of constraints and supports

Ebersold (2008) suggests that we can determine the ability of an institution to change and respond to societal demand through the support it renders to its disabled students.

In Tanzania, disabled students in HE were first admitted to university in 1978, 17 years after the establishment of HE in the country. They were two male students with visual impairment and were admitted to the University of Dar es Salaam. Since then, disabled students have been admitted although, as mentioned above, their access has been limited. This indicates that there are limited chances of changing the traditional HE student population, which could be what Archer (2000) calls a morphostatic transformation cycle of HE.

Besides that static cycle of HE, support for disabled students has been minimal. Funds which would support disabled students in all phases of education in terms of physical infrastructure and supportive devices have remained limited. Universities have had limited resources to adequately provide their students with accessible buildings and/or supportive devices and services. According to NDS (2008), most public buildings in Tanzania, including schools and HE institutions, cannot be easily modified to support the mobility of disabled students. Likewise, Morley et al. (2010) point to inaccessible buildings for disabled students at some universities in Tanzania. In contrast, Tuomi et al. (2014), who conducted their study in one university in Tanzania, suggest that it had renovated a few of its buildings to make them more accessible. They also inform us, however, that in the buildings which were not renovated there was no provision to allow the easy movement of physically-challenged students. This observation does not differ from the findings of my own research. In my research, Joshua, a male teaching staff, talks about witnessing a student at his university crawling on the stairs to attend classes on the third floor, which shows the lack of supportive services to facilitate students' access to all university buildings. This can indicate that the university management lacks a commitment to support or include disabled students in their university, and therefore its limited ability to respond to demands made by social groups, including those of disabled students in HE. Contrary the 14 students with albinism mention their positive experiences as the assurance of university accommodation. For the 14 students with albinism university accommodation was an assurance for their security and safety. Thus giving them a feeling of being valued and accepted.

None of the 14 students with albinism in this study were physically challenged or directly affected by inaccessible buildings. However, Angel, Deborah, Simon, and Lucas all talk about inaccessible buildings, not because of their immobility but because of their poor

vision, particularly during the hours of darkness. Their concern was the non-availability of proper lighting systems on campus as it was often difficult and threatening for them to walk in darkness from one building to another, either to attend evening or night lectures or when using the library after the hours of daylight. In some cases, they had to avoid attending classes or using the library because of the lack of support services or arrangements that would enable their safe and smooth movement across the campuses. The lack of adequate campus light, reliable Internet services to access electronic books or journals, or security escorts were among the facilities that they mentioned as lacking.

The same four students explain further how poor lighting affected their learning process and thus could have hindered their successful completion of HE. For example, Lucas says:

(w)hen I was at university we had an examination at the [name of the building]. That room's lights are so dim. I once had my [name of course] examination in that room at around 18 hours in the evening. I was looking at some numbers and asking myself, is this eight or six? You end up getting a 'C' when you did not deserve to get a 'C' because when the bulbs blow out they are not replaced. (Lucas, male graduate with albinism- MSES).

There are several messages in Lucas' reflection. On the one hand, Lucas, as Archer (2007) would say, is making a running commentary on what is taking place in the examination processes and thus internally warning himself about the possibility of having poor grades. On the other hand, there are implications that his university does not have a culture of making the necessary pre-examination arrangements for its students with various differences. Arrangements for students like Lucas would involve having designated, well-lit examination rooms for students with poor vision. Meshack talks about similar experiences. He reflects upon how he did so well in his discussions with his fellow students that he would sometimes guide and support them with their learning but that when it came to examinations, he would perform poorly because sometimes he could not see what is written on the papers.

Like Lucas, Meshack associates his unsatisfactory performance with poor classroom lighting, as well as the small fonts on examination papers. Meshack also talks about how the university management were surprised when he failed his examinations and enquired into the cause of his failure. When they realised the causes, Meshack says the

university began to set his examination papers in large fonts and ensured proper lighting in his examination rooms, as well as arranging for him to sit near the window. Meshack's case resembles that of Martha, upon whom David reflected in Chapter Five. They both influenced university systems to change ways of preparing examination, by enlarging fonts. Thus Meshack and Martha have, as Archer (2000) points out, acted to change the examination structure and culture of small fonts.

Happiness and Deborah have almost similar experiences to those of Lucas and Meshack. Their universities also introduced services and arrangements to enlarge their examination papers after they had had unsatisfactory examination results, showing that some HE institutions in Tanzania do not have wider institution examination services or arrangements to support the entire disabled student population, but rather provide support for them on an ad hoc or on individual basis. Except for Peter, who completed his university education in 1993, other students with albinism say that their examination papers were in enlarged fonts. Likewise, except for Peter, other students with albinism were given extra or increased examination time, indicating that some universities had in place assessment procedures to support disabled students with poor vision, like students with albinism. None of the 14 students with the condition, naturally, were given longer deadlines to complete their assignments. The practice, which was causing anxiety as the 14 students with albinism talked about the lack of provision for longer deadlines and later expressed their fear of failing their examinations.

As mentioned several times in this research, students with albinism have poor vision and therefore need supportive devices to facilitate their learning. Luande (2009) and Lynch and Lund (2011) inform us that for people with albinism to learn successfully, they need supportive devices such as magnifiers or monoculars. Students with the condition can thereby adequately read what is written on the board or clearly see the face or non-verbal instructions of teachers. Despite the usefulness of magnifiers or monoculars in the learning of students with albinism, none of the 14 students with the condition were provided with such devices, even when they cost less than braille.

The three universities in Tanzania which admitted disabled students provided braille to their visually-impaired students. However, none of the nine students with albinism at these universities were provided with magnifiers or monoculars. This could be interpreted

as suggesting that these universities give less importance to the learning or inclusion of students with albinism in HE, or that students with the condition are treated less favourably than other students with disability. However, students such as Sarah, Grace and Thomas, who were all from the same university, were provided with students' readers (notetakers) to supplement devices like magnifiers or monoculars. Readers, as reflected upon by the three students, assisted them with note-taking and also reading. They also helped students search for reading materials from the library, as well as from the Internet. The respective university pays them for three hours every day for seven days a week for such services. The provision of readers contradicts my earlier interpretation that students with albinism were provided less support as compared to other students with disability.

Although, Sarah, Grace and Thomas acknowledge the contribution of readers, Sarah says: (b)ecause some classes are crowded you cannot always decide to sit with your notes takers. In some cases they may either sit in front or at the back, therefore you find yourself not sitting with them. Therefore when you ask a person sitting next to you "what did the teacher write on the board", the person would reply "why don't you look, can't you see", so I struggle myself or I wait for my note takers. (Sarah, female student with albinism-LSES).

We are aware that Tanzania has, for a number of years, faced an economic crisis, which to some extent has affected the government's ability to adequately fund its education system. This reality has had adverse effects on the availability of essential teaching and learning facilities in some public and private HE institutions. Some universities in Tanzania do not only have limited teaching and learning materials, but also limited desks and lecture rooms thus resulting in some overcrowded lecture rooms. This way although Sarah, Grace and Thomas were happy and liked the provision of readers, they tell us about the barriers in the provision of readers in an environment where classes are overcrowded. Sarah says: (s)ome lecturers come into the class with a projector and transparencies, something which I cannot see. Until my note takers, who are paid by the institution, write and later read back for me then I can do my revision. But they are also students and not employees; they are not there for me all the time because they also have their own assignments and other activities. Added to that, the official time they are paid for supporting me is only three and half-hours per day (Sarah, female student with albinism- LSES).

This could mean that the availability of readers (notetakers) can either constrain or support students with albinism. For this reason, the provision of supportive devices such as monoculars or magnifiers is essential. Like Grace and Thomas, Sarah has two students' readers who support her with reading and notes-taking. But the culture of appointing readers is increasingly challenged by the structure of crowded classrooms resulting in what Archer (1996) calls interpenetration. For Archer, interpenetration is the intersection between cycles of structural and cultural morphogenesis. To mediate the interpenetration, Sarah wakes up early in the morning so that she can be in class before it is crowded. However, this mediation is sometimes constrained when she has to attend one class immediately after another as she says she cannot walk fast enough to arrive in class before others because of her poor vision. Here, Sarah's agency is restricted by the actions of other agents (Archer, 2000).

Like Sarah, Mary, a student reader, also indicates the importance of the provision of supportive devices when compared to the provision of readers. Mary says that sometimes because of crowded classes she cannot adequately perform her work as a reader or note taker, as sometimes she has to depend on other students' notes. This is when she cannot arrive on time to have space in class or to sit next to the student she supports. In this context, as Archer (1995) points out despite the good intentions of people some structure can resist change. The structure of non-conducive learning environment for students with vision impairment resists change despite the institution good intention of providing them with readers.

Mary also reflects upon how her university works to limit rather than foster her agency as a reader, implying that although her university has good intentions to enable students with albinism, the structure of the university in terms of infrastructure does not accommodate the system of readers. Here Mary also talks about her own workload which sometimes does not allow her to efficiently provide her support as a reader. Although the support system that Mary talks about was not always effective in enabling some students with albinism, Sarah, Grace and Thomas felt it was beneficial because it allowed them to have students whom they could call friends which enabled their inclusion in the university student community.

Lucas, Isaack, Peter and John, who graduated from the university that Sarah, Grace and Thomas attend, say they did not have the opportunity to be provided with readers. These four graduates with albinism say that before 2009, their university only provided readers to students with visual impairment and that they mostly depended on the support of other students to give them notes, as indicated and thoroughly explained by Deborah in Section 6.3. This reflection further shows that students with albinism have been given less support than those with other disabilities. Likewise, Deborah, Angel, Loveness, Happiness and others such as Meshack and David, who were studying in universities which do not have systems to support students with various disabilities, including poor vision, also depended on the support of other students to participate in HE.

Similarly, although Simon was studying at one of the three universities which admit disabled students, he also depended on the support of other students for his notes taking because his university does not have a reader system and neither does it provide supportive devices such as magnifiers or monocular. This is despite the fact that it provides its visually-impaired students with braille and other specific services. Simon's case further shows that visual impairment and albinism were widely given less recognition or support in Tanzanian universities. I can therefore say that disability is inflicted over their visual impairment (Union of the Physically Impaired Against Segregation (UPIAS), 1976), thus constraining their agency.

While there were differences in the provision of support services between universities, there were also differences within faculties of the same institution. For example, Sarah says:

(s)tudents with disabilities in the Faculty of Education have better supporting services; this is because their teacher are more aware about issues of disability and when the support unit was first established it was meant to support students in the Faculty of Education. (Sarah, female student with albinism- LSES).

Archer (1984) informs us that education systems often have particular structures, which are largely influenced by those who control them. This could mean that the Faculty of Education at Sarah's university had better support services because those who controlled the faculty gave particular attention to students with albinism.

One of the students with albinism in this study, who was a student at the Faculty of Education, agrees with Sarah's reflection. James, Paul, Titus and Timothy, who are support staff at Sarah's university, also agree with her. They say the initial purpose of admitting disabled students was for the Faculty of Education to teach visually-impaired students who were themselves to teach in schools for visually-impaired students. The faculty later involved students with hearing impairment who were also meant to teach students with a similar impairment.

Showing that support services were more geared toward the Faculty of Education and not to programmes across the entire university, the four support staff mention that even the coordination and management of the support unit at their university is currently under the Faculty of Education. As for Sarah, she says:

(i)n other programmes to be honest the lecturers have no knowledge at all about issues of people with disability. Actually for me it is just like when I was in primary school or in other places. They treat all of us as normal students. (Sarah, female student with albinism- LSES).

Talking about the support that they received from teaching staff, Happiness and Loveness share the same sentiments as Sarah. They feel that some teaching staff were not conversant with teaching students with poor vision like themselves. Likewise, the six teaching staff (Joshua, Elizabeth, Ruth, Azaria, Steven and Yerima) whom I interviewed talk about their limited skills and training in teaching students with albinism. Some of them had been primary or secondary school teachers prior to teaching in HE. Ruth, for example, a female teaching staff who had been a secondary school teacher, was not aware of the poor vision that student with albinism often experience, which could structure her teaching and assessment of students with the condition. Like Ruth, other teaching staff as reflected upon by Loveness, Happiness and David in Chapter Five were not aware that students with albinism often have poor vision.

Azaria is also a female teaching staff who participated in this research. She had been a primary school teacher prior to her HE teaching and says that although she had no training for teaching students with special needs she was sympathetic towards one of her pupils who had albinism, allowing the pupil to sit in front so as to see the board clearly. This is a good example of agency, but there are emotional implications: teachers' support

would depend on who had the personal concern and generosity to offer it. Lynch and Lund (2011) suggest that in teaching students with poor vision like those with albinism, teachers should place the children near the board or near the window, helping the child to see what is written on the board. By placing the child in front, Azaria enabled the child's learning and thus included her in the learning process.

Joshua is another member of teaching staff who also has no training on teaching disabled students. Implying his own reflexivity, he says although he has no training of teaching disabled students, he is careful in his teaching not to use words that would offend students who are different. He also talks about issuing printed notes as well as his email contacts to disabled students in his class. However, he says he does not always issue printed notes before he knows the number of disabled students in his class because he is not previously informed about students with special needs, implying that the university does not expect or believe that such students will attend and therefore makes no preparations to accommodate or include them in their teaching and learning plans. As the general assumption was that university was not a place for disabled students (Riddell et al., 2005: 4).

Joshua says that although he could easily tell the number of students with albinism in his class because of their appearance, he could not know when there were students with hidden impairments. He therefore sees the lack of prior information about the numbers of disabled students and the nature of their impairment as constraining his agency to support students with albinism, because he cannot prepare printed notes before the lecture sessions. In support of Joshua's reflection, the four support staff mentioned above, who work for a support unit at Joshua's university, agree that their unit does not provide teaching staff with details of students with special needs because they do not have such information prior to student enrolment. According to them, such information is only available after students register with the unit. Archer (1984) informs us that the education system has particular relations with society. In this context, and based on society's practices and attitudes towards albinism, as discussed in Chapter Four, I would say that the university is less concerned with the learning of students with albinism. Contrary to this view, the four support staff say that given the limited numbers of residential rooms on campus, when disabled students register with the unit as already mentioned their names are sent to the housing department for priority allocation of rooms, demonstrating the concern of the university and the support that it renders.

In a previous chapter, I indicated how emotions stick to albinism, showing that students with albinism were likely to require services which would support emotional and/or psychological problems. Although such problems often require counselling services, none of the 14 students with the condition had access to these. All five support staff agreed that counselling services were important for the inclusion and learning of students with albinism, but were not available at their university. Elizabeth, who is an expert in special needs issues, reflected upon Judith's suicide by talking about the need for counselling services, which were also not available at her university.

In this section, I have, to a large extent, discussed social structures which often constrained the inclusion of the fourteen participants with albinism in HE. I have also indicated the support services that HE institutions have in place for their disabled students, including those with albinism. Archer's (2000, 2003, 2007) theoretical framework of structure and agency, upon which this thesis draws, stipulates the interrelationship of the two elements of social reality, namely social structures and human agency. Archer (2000, 2003, 2007) sees the connection between structures and agency taking place through people's internal conversations in which they often reflect upon themselves in relation to their social environment. She says that people often issue warnings to themselves, make personal promises, plan for possible future events, clarify their positions and reach decisions and conclusions. She thus sees internal conversations as enablers of personal agency which often support people to mediate their constraining structures.

This research contains participants' reflections, particularly those of the fourteen students with albinism, which I can refer to as internal conversations, in which some of the fourteen students with albinism were warning themselves, making promises to themselves, planning or reaching decisions and conclusions. One such example is Happiness' reflection that 'I would say to myself I also want to go, why shouldn't I go to Form Five'; or Isaack's reflection that 'I asked myself was this really me or somebody else? It was a motivating academic performance'. Another such example is Thomas' reflection that 'I was thinking if I fail I would be discontinued from university, so I had to study hard'. As for David, he says:

(I) thought if in my advanced level education, I can score division one then let me go and be an example, especially for some people who have a negative perspective about people with albinism. (David, male graduate with albinism, LSES).

Archer (2007) tells us that when people are faced with structural constraints in life they often have conversations with themselves about how to mediate those constraints. Analysing David's reflection above, I can say that David was internally having a personal conversation and contemplating the challenges of marginalisation that he was facing as a person with albinism. Through his internal conversation, I can also say that he was thinking that, despite his outstanding academic performance, people with albinism were often portrayed as having no agency. David thus concluded that such challenging discourses would change if he were to enter HE. Here David, through his internal conversation, might have made a decision and plan to join HE so as to show that people with albinism are capable human beings.

Like David, Happiness', Isaack's and Thomas' internal conversations, quoted above, indicate that they were having encouraging or motivating internal conversations. In Happiness' case, I can say that she was promising herself that she must join Form Five and consequently enter HE. As for Isaack, he was being internally motivated and encouraged by his academic performance, whereas Thomas was warning himself to study hard so that he could continue with his studies.

While the four participants' internal conversations, indicated above, might have enabled them to interact with HE opportunities, there were cases in which some students with albinism in this study were internally discouraging themselves. For example, Loveness, as I have already mentioned, thought of dropping out of school. It was only after her parents and sibling supported her that she was able to progress to HE. Likewise, Sarah says that when she failed Form Four she had no plans of continuing into HE. She says it was her mother who had encouraged her to progress to HE. Deborah, similarly, says:

(b)ut then things were beginning to be difficult, I could not handle everything so I decided to leave college and continue with work. (Deborah, female graduate student with albinism, LSES)

Archer (2007) says that our internal conversations or silent voices can sometimes limit or discourage us from accomplishing our plans or life goals. Thus, Deborah's internal conversations and those of Loveness and Sarah seem to be discouraging them from accomplishing their life goal of entering HE. However, Archer (2003, 2007) says that when people have discouraging internal conversations they can be supported by

communicative reflexivity (see section 6.2) to achieve their life goals. Communicative reflexivity, according to Archer (2007), can be with family members, relatives, teachers, peers and other human agencies. The life goal of Loveness, Sarah and Deborah to enter HE was also supported by communicative reflexivity with their family members, relatives or people from their communities.

As mentioned in Chapter Two, studies in Tanzania reveal that parents or family members play an important role in motivating or encouraging their disabled children to enter HE studies (Morley & Croft, 2011; Tuomi et al., 2015). In my research, the data also reveal similar patterns. For example, Loveness talks about how her mother went to the National Examination Board of Tanzania and requested that her standard seven final examination papers be printed in enlarged fonts. Given such support, Loveness links her entrance into HE with support from her parents, particularly her mother. Loveness is not the only participant who associated her academic success with her parents. John and Lucas also believe that their parents had an important role in motivating and encouraging them to progress to HE. Eliza, who is a mother of children with albinism, says:

(I) always told them whenever they reached Form Four, I don't want Form Four any more, I want Form Five and Form Six. When they reached there, I would tell them I want a first degree and when they got their first degree, I said I want a PhD and now they have it. (Eliza, mother of children with albinism).

Given that Eliza's children progressed to HE, Eliza's reflection is an indication that parental encouragement and motivation contribute to the interaction of students with albinism with HE as Eliza's continuous involvement in her children's education had a positive outcome. The study by Tuomi et al. (2015) also points to parental encouragement as one of the key factors enabling their women participants to participate in HE.

Given that Tanzanian culture often encourages the support of family members (see section 1.2), the fourteen students with albinism also mention such support; Isaack, for example, mentions how his young brother was his role model in negotiating his way into HE. Sarah points to her grandmother's financial support while David also talks about his uncle's financial support. These reflections indicate that, in Tanzania, family members were significant enablers for the participation of students with albinism in HE, especially given that government and institutional supports for students with albinism is often limited.

While the fourteen participants with albinism talked about the moral and financial support from their parents and family members such as grandmothers, uncles, aunts or siblings, they also talked about the role that some of their teachers played in enabling them to enter and succeed in HE. As mentioned in Chapter Two, studies in Global North and Global South countries, including Tanzania, indicate that teachers of all phases of education are an important group in supporting the motivation and aspiration of students with disabilities. In my study, Sarah talks about how she was enabled by four teachers who had skills in teaching students with vision impairments. Thus, she passed her Standard Seven final examinations (also see section 6.3). Likewise, Loveness, who wanted to undertake a career in health-related programmes, had to undertake science-related subjects in her pre-university education and says:

(h)olding chemicals was a challenge, especially when I was near the window or when it was windy. But I managed most of the practicals because my Chemistry teacher was supportive. He taught me the techniques of holding a test tube and being able to see the chemical inside. (Loveness, female student with albinism, MSES).

Loveness' reflection emphasises the significance of teachers in supporting students to succeed in their desired course programmes, particularly students with low vision like those with albinism. This is because it might have been impossible for Loveness to undertake her desired science-related career if it were not for the support that she received from her teachers, including her chemistry teacher who taught her how to adequately use science-related learning materials.

Fuller et al. (2004) say that teachers' attitudes towards students can either be a barrier or an enabler. In Loveness' case, her teacher's positive attitude towards her desires can be one of the reasons that Loveness was enabled to undertake a programme of her choice.

Like Loveness, David talks about how his teachers' positive attitudes towards him motivated him to do well in his studies. He believes that his teachers' positive attitudes and motivation were what enabled him to successfully complete and pass his 'A' level examinations. As for Peter, he says:

(m)y standard one class teacher understood my situation so after teaching other students she would then explain to me what she had written on the board and taught, so I did well in class (Peter, male graduate with albinism, LSES).

Gavira and Morina (2014) believe that teachers' positive attitude towards disabled students is an essential supporting network for their successful learning. They suggest that to create a better supporting system teachers, including those in HE institutions, must show interest and concern in the learning of disabled students and be committed, and willing to help them in their learning. Jacklin (2011) says that when teachers are teaching groups of students who have different learning abilities, they cannot teach them all in the same way. I believe Peter's teacher recognised this and was thus willing to set some time aside to explain to him to ensure that he understood what she had taught. Committed teachers are likely to make this sort of effort.

The education system in Tanzania has yet to put in place fully supportive arrangements for disabled students (see sections 1.8 and 6.4). When an education system is not fully inclusive, Barnes (2007) suggests that teachers, including those in HE, need to be innovative. Operating in a partially inclusive system, Joshua, one of the HE teaching staff in this study, as indicated above in section 6.4, talks about his innovations. He talks about how he attempted to identify students with special needs in his class so that he could support their learning by providing written materials and accessible examination papers. Gavira and Morina (2014) say that when HE teaching staff have a positive attitude towards the learning of disabled students, they often provide them with care support and written materials, set accessible exams and ensure that they can be contacted at all times through email. In this way, Joshua and the other five teaching staff in this study, namely, Elizabeth, Ruth, Azaria, Yerima and Steven, were sources of support to students with albinism in HE institutions in Tanzania.

6.5 Summary

This chapter was the last of the three chapters in which the findings of the study are presented and analysed. This chapter analysed constraints and enablers in the form of social structures and agency in the life experiences of students with albinism in their goal to be HE students. The chapter focuses on the students' experiences in relation to socio-economic positions, teaching practices, teaching and learning materials and support services. The key findings are summarised below.

Social theorists are yet to agree on a definition of structure or agency and debates on these two aspects of social life are still ongoing. Some of these debates give emphasis to structures, while others give primacy to individual agency in shaping human action. Still others, such as Archer (1995; 2000; 2003) and Giddens (1984), give importance to both structure and agency, though they differ as to how the two elements of social life should be studied. Archer (1995) believes they can be studied separately as they work on different timescales, while Giddens (1984) suggests that they could be studied together as they operate simultaneously.

My research draws upon Archer's (1995; 2000; 2003) dualism analytical approach, which allows social structures and human agency to be studied separately, but with a view that they are interrelated as they shape and influence each other. In this context, I was able to analyse the structural and agential social life of the 14 students with albinism and then linked their agency with various social and cultural structures which they often encounter when interacting with HE opportunities. This link has provided an explanation as to how the 14 students with the condition interacted with HE opportunities amidst the social and cultural structures and was made possible through Archer's (1995; 2000; 2003) notion of reflexivity and internal conversation.

Archer (1995) tells us that as human beings we all possess personal properties, which are our creativity, desires, memory and so on. These properties Archer (2007) believes cannot be constrained by any social or cultural structure because they are internal and unspoken, and therefore not known by the social world. In this research, the 14 students with the condition used their personal properties to overcome various barriers that constrained their inclusion in HE. Among such properties were their creativity, memory, desires, personal promises and various strategies which enabled their interaction with HE opportunities. Some of the strategies were unique to themselves as students with albinism while others were unique to individual students. For example, Thomas had a unique strategy whereby he would explain to his fellow students while such explanations simultaneously allowed him to be learning from them. Happiness, on the other hand, chose to concentrate on only five subjects when she realised that the teaching style was static and could not be easily changed to support her learning.

According to Archer (2000), some structures can resist change. Higher education in Tanzania has resisted changing its traditional students' structure. Despite widening participation strategies, it continues to deny full participation to non-traditional students like students with albinism. This is because the teaching and environment remains geared to particular types of students thus constraining others who are thought to be out of place. Non-traditional students like the 14 students with the condition have been retained and some, like the seven graduate with albinism, have completed their studies because, as Archer (2000; 2003) would argue, they have concerns and formulated projects to accomplish.

Students in this research had various concerns but the ultimate concern, shared by all, was the concern for self-worth. They were all concerned that they were often discriminated against, humiliated and mistreated and therefore wanted to be recognised, respected and valued. They believed that by having HE qualifications, they would overcome discrimination and mistreatment and formulated the project of being HE students, which they then achieved with the support of their own agency and other agential support. What was clear was that some students with albinism, such as Happiness and Grace, showed extraordinary agency.

The following chapter reflects upon the research findings which emerge from my three analysis chapters, which have focused on emotions, misogyny and structure and agency. The chapter also provides key policy and practice recommendations as well as suggestions for areas of future research.

Chapter Seven

Conclusion and Recommendations

7.1 Introduction

In this thesis I have reported the constraints to and enablers of the 14 students with albinism in their educational participation. I began my research journey set to seek the perceptions of 35 participants on the lived experiences of students with albinism in interacting with HE opportunities. As a part of this, I sought some insights from the participants about the factors that constrain or enable their interaction with, and consequently participation in, HE. These experiences, I felt, were barriers for students with the condition to fully participate in education and society at large. I thus portrayed my PhD project as a journey during which I did not only gain insights into the life experiences of students with albinism, but also into my own life. In this journey, I learnt that studying gender and power relations, particularly when focusing on pain and oppression, could cause hurt, grief and anger. This was because my research process, especially that of transcribing, was filled with the emotions caused by being seen and treated as the ‘other.’

My journey as a feminist researcher challenged some of my assumptions and raised my awareness of the importance of collective agency from feminists. This was after I received continuous support, pushing, encouragement and sacrifices from various women, particularly my two supervisors. I realise that, despite my commitment and hard work towards my PhD journey, without that very continuous and honoured support from my main supervisor and others, my valued and long-awaited journey might have been delayed indefinitely or never have come to an end. My challenging but rewarding PhD journey therefore has led me to a new understanding of feminism, which I have promised myself to emulate. It is now much clearer to me that, as a woman, I have to support other women of all ages as well as other oppressed groups in their endeavours to overcome the structural and cultural constraints that have often been imposed on us by patriarchy.

I began this research with agency in mind because I sought to understand the experiences of students with albinism in HE. If I were to do it all over again, however, I would also have in mind the concept of structure and therefore also seek the experiences of those

who had not succeeded in accessing HE and interview them so as to explore their non-participation. I came to this decision partly after extensive reading on emotions, symbolic violence, structure and agency debates, as well as misogyny. Equally, my decision has been influenced by the in-depth and rich interview data from 14 participants with albinism on their socio-cultural, economic and impairment life experiences.

Nevertheless, the data I gathered in this research is in-depth, and rich and thus I believe it delivers the kind of research that I envisaged. Therefore, in this chapter I revisit my research questions and discuss them in relation to my theoretical framework, research findings and the existing literature. This allows me to provide the key factors that enabled or constrained the successful participation of students with albinism in HE. I then present key policy issues that emerged from my findings, thus providing implications for practice, and the main contributions of my research. Followed by recommendations for action at national, institutional and family level. Finally, the chapter suggests areas that may require future research.

7.2 My theoretical Framework

The discussion of this thesis was focused around the themes that emerged from the reflection of the participants in this research, from which I identified three interrelated factors influencing the experiences of students with albinism in their interaction with HE opportunities. These themes, which also formed the basis for the literature review and analysis sections of this thesis, were emotions, misogyny, and structure and agency. These three emerging themes, although they are interrelated, were an indication of the complexity surrounding the life experiences of students with the condition. It was therefore felt that no single theory could capture the multidimensional challenges that often face people with albinism. In this context, I felt that the use of a single theory would lead to situations where important experiences in the lives of students with albinism would remain unexplored or unexplained.

I therefore used four main theories to analyse the experiences of students with albinism through multiple lenses. Here I drew upon Sara Ahmed's (2000; 2004a&b; 2012) notion of affective economies and stranger dangers to analyse how emotions that circulated around albinism align those without albinism against those with albinism. Pierre Bourdieu's

(1984) work on symbolic violence was linked with Ahmed's (2000; 2004a&b; 2012) notion to analyse nuanced domination and subordination produced through emotions. Likewise, de Beauvoir's ((1949[2011])) and other feminist theorists' concepts of misogyny, i.e., the hatred, fear and oppression of women, were also linked with Ahmed's (2000; 2004a&b; 2012) work to analyse the activation of misogyny or issues of misogyny in the lives of students with albinism or women with children with albinism. Bourdieu's (1984) notion of symbolic violence and feminist theories of oppression fitted well with Ahmed's (2000; 2004a&b; 2012) wider theory of difference because they could all help explain the complexity of emotions.

I also believed that Archer's (1988; 1995; 2000) theory of morphogenesis and her concept of reflexivity fitted well with Ahmed's (2000; 2004a&b; 2012) wider theory of difference and her notions of affective economies and stranger danger. This was because Archer's (2003) framework of analytical dualism enabled me to analyse enablers and constraints experienced by students with albinism and link them to her notions of reflexivity and internal conversation, which provide explanations as to the courses of action taken by students with albinism in a world which Ahmed (2000; 2004a&b) sees as circulated with emotions that stick and create boundaries. This enabled me to explain how the 14 students with albinism were able to participate in HE despite various social and cultural structures which Ahmed (2000; 2004a&b) calls emotions or boundaries and de Beauvoir ((2011[1949])) calls misogyny that they often experience.

7.3 My key findings

As already mentioned, my hope for this study is to contribute to the understanding of disability in HE in relation to the participation of students with albinism. I therefore discuss my key findings by revisiting my research question: 'What are the experiences of students with albinism in interacting with HE opportunities in Tanzania?' Within this research question, I also revisit my research sub-questions:

1. Where are students with albinism located in HE in Tanzania?
2. What are the barriers and enablers to their participation in HE, e.g., support from teachers, families, and communities?
3. What are the motivations for students with albinism to enter HE?

4. What are the life experiences of inclusion/exclusion in different phases of education?
5. What are their HE academic experiences, e.g., of teaching and learning, assessment and learning support?
6. What specific support is in place for students with albinism?
7. What needs to be done differently to enhance the participation and achievement of students with albinism in Tanzanian HE?

I will now review my findings in relation to each research question drawing on my empirical data and the appropriate literature.

In relation to Question One, the exploration of where students with albinism were located in HE in Tanzania was more difficult than I had expected. The data necessary to answer this question were not readily available; indeed, it took several telephone calls to obtain the data I required. The absence of readily-available data was an indication that students with albinism were often given a low profile in policy contexts. According to Graham (2014), a group that does not feature in the data suggests exclusion or misrecognition. It is likely that the particular group will be omitted from plans thus excluded from institutional or governmental resources. The experiences of students with albinism in this study clearly reveal omissions in resource allocation and consequently, exclusion in all phases of education.

Despite this exclusion, there were 20 students with albinism located in 12 universities of the 52 universities in Tanzania. Of the 20 students with albinism, eight were female and the rest were male. This finding does not differ from the existing literature, which indicates that more male disabled students enter HE than female (Barnes, 2007; Mumba, 2009). In terms of programme location, the 20 students with the condition were found to be in different degree programmes although the majority were in the law and social sciences cluster. A few were in the BMA, education, arts and sciences and medical sciences, but none were in agriculture, natural science or STEM programmes.

The absence of students with albinism in the last-named three clusters can be associated to the requirements of those programmes. Borland and James (1999) suggest that the requirements of some programmes exclude disabled students on the basis of their physical ability. Borland and James (1999) give examples of programmes such as archaeology,

which automatically excludes students with vision or mobility impairments because of requirements for excavation fieldwork. The fact that there were no students with albinism in the three science-related clusters could indicate that some programmes exclude them, especially when Lucas, John and David could not take science-related programmes because of the practical aspects of such programme. Science-related programmes are often categorised as highly marketable programmes (Morley, 2006; Grenz et al., 2008). The absence of students with albinism from these programmes means they are located in low-marketable ones, which is likely to have an impact on their future socio-economic status.

In addition to programme location, my findings also reveal that students with albinism were located in private universities. Given the long-term establishment of public universities, entry into them is relatively competitive (Cooksey et al., 2003). Despite stiff competition in entering public universities, eight of the 20 students with the condition had gained admittance. Although my data show that there were fewer students with albinism in public universities than in private universities, the data from the 14 students with albinism who participated in this study indicate that 11 of them were in such universities. Given the barriers that students with albinism often face, the limited support that they often receive as well as the stiff competition that entails entering public universities in Tanzania, the location of 11 students with albinism in public universities demonstrates extraordinary agency.

Literature indicates that disabled people in Tanzania often live in rural areas (NDS, 2008). Exploring further my sub-question one, in view of such literature, my research indicates that of the 20 students with the condition, only two were studying at universities in rural areas. As for the 14 students with albinism participating in this research, only one was at a rural university. These findings therefore suggest that although disabled people including people with albinism are often in rural areas, when they interact with HE opportunities this can also mean urban living. Urban areas in Tanzania tend to have better health and socio-economic services and facilities than those in rural areas (Human Development Report, 2011).

Regarding my sub-question two, which explores the barriers and enablers to the participation of students with albinism in HE, I specifically focus on the barriers imposed, or enablers provided, by teachers, families and communities. In terms of barriers, the

perspectives of the 35 participants demonstrate that albinism was laden with emotions such as fear, hatred and ambivalence. Thus these emotions were circulated through myths and beliefs which worked to construct people with albinism as different and creating a hegemony that enabled those without albinism to dominate those with albinism. My findings also demonstrate that mythologies and beliefs had also constructed a particular normative type of humanity, which is seen as an accepted way of being human in Tanzania. As schools and HE institutions are part of the society and they operate within the culture of the society (Chataika, 2007), my findings reveal that schools and HE institutions also adopted their ways of being as demonstrated by the bullying, harassment, abuse, and symbolic violence frequently experienced by the people with albinism including students with albinism.

Likewise teachers, families and members of communities do not live in isolation: they are part of society. Therefore, what is embedded in the society is likely to be reflected in their actions. The experiences of students in this study reveal that some teachers did show a deficient understanding: rather than providing appropriate learning support to them as students with poor vision, some teachers, as indicated by Sarah, Happiness, and Lucas placed them in a passive position and not as agentic individuals. Thus labelling them 'lazy', 'witches' or 'stubborn' consequently constrained their learning. However, not all students in this study were constrained by teachers. For example, Grace's teachers in primary, secondary, and even HE were, as she revealed, great supporters in her academic progress. Teachers' support in terms of encouragement had, to a large extent, enabled Grace to obtain excellent academic results at all stages on her education ladder. Likewise, Sarah's support from her four teachers (see Section 6.3) further revealed the importance of teachers' support and recognition of difference in the participation of students with albinism in HE.

In further exploring my sub-question two, the experiences of the 14 students with albinism also point to parents or family members as barriers or enablers. Parents' misconception of children with albinism, as poor investment, limited parental support thus constrained students with albinism participation in all phases of education, including HE. Thomas' participation in HE, for example, was delayed because his father refused to pay his school fees by believing that Thomas had low cognition ability. Isaack and Peter had similar experiences as they were assumed to have the same.

While my findings reveal that misrecognition was a barrier to the interaction of students with HE opportunities, fathers' shame was another barrier. Ester, Philemon and Elizabeth indicate father's shame when they reflect upon how children with albinism are often brought up by their mothers. Ahmed (2004b) says that shame can turn to denial. This denial is clearly revealed by the experiences of six students with albinism in this study who had to be supported by extended relatives, NGOs or sympathisers to interact with HE opportunities. Literature acknowledges the importance of parental support and encouragement in the academic success of students (De Broucker and Underwood, 1998; Ndalichako and Komba, 2014). Therefore, when parents cannot adequately support the education of their children, because of shame the participation of their children in education was likely to be affected.

Tanzania is mostly a patrilineal society. Being a patrilineal society means that the 14 students with albinism automatically took up their fathers' kin. It is more likely that in a patrilineal society fathers expect or wish to have children, who will continue their kin, so as to demonstrate their masculinity. In cases where their masculinity was threatened, fathers as demonstrated by Angel, Happiness, Sarah and David protested by rejecting their children. Given the FHH poverty (Chant, 2006) and given that fathers in Tanzania are often major family supporters (Demographic and Health Survey, 2010), defence of masculinity can constrain the participation of students with the condition when fathers abandon their supportive responsibility. Such constraints are demonstrated in Sarah's experiences who dropped out of college due lack of such support and Angel who was subjected to sexual exploitation because of FHH poverty.

My findings do not only indicate that parents can constrain the education of students with albinism but also that they can enable their education as indicated by Eliza, Loveness, John and Lucas. Eliza, who was mother of children with albinism, for example, demonstrated how she had encouraged and financially supported her children to enter HE. To do so, she bought them desks for a comfortable learning and also encouraged them to continue with studies to the highest level of the education ladder. Loveness, John and Lucas also had the same encouragement from both parents, including their fathers. The encouragements and the resources that Eliza provided to her children and that the three students with albinism received from their parents were enablers that supported their smooth interaction with HE.

Thus parental and financial supports were seen to be enablers towards the participation of students with albinism in HE.

My third sub-question, which focuses on factors which motivated the 14 students with albinism to aspire for HE, responds to these findings. In addition to parental encouragement, there are other factors which had motivated the 14 students with the condition to aspire for HE. For example, Grace, Angel, David, and Sarah, who had LSES, they desired to get out of poverty. As for Loveness, Lucas, and John, with MSES, their wish was to be financially independent and their motivation was also seen in their beliefs that HE was the norm of the family. My findings do not differ from those of (Morley and Croft, 2011; Opini, 2014; Tuomi et al., 2015), as they all reveal that disabled students in SSA were often motivated to enter HE for social and economic reasons. However, those with LSES were seen to be motivated by the desire to break out of the intergenerational chain of poverty while those with MSES were motivated so that they maintained their socio-economic status by being financially independent. Thus students of different socio-economic status were seen to be motivated differently.

Other factors found to motivate students with albinism to enter HE, as revealed by the 14 students with the condition, were to gain respect, and be seen as valuable members of society, and the fact that HE was seen as a source of pride. My findings suggest that the 14 students were inspired by different factors to join HE, but the common motivating factor, mentioned by all of them, was to be an agent of change. Here, the aspiration was to improve the socio-economic lives of other people with albinism. This meant that the 14 students with albinism were also motivated to seek HE not only for personal socio-economic benefits, but also for the benefit of other people with albinism. Archer (2000) informs us that peoples' wish for advocacy was on the increase. The aspiration for advocacy shown by students with albinism was a positive motivation and should be nurtured and encouraged, as it will not only improve the participation of people with albinism in HE but will also empower them to collectively advocate for recognition and inclusion in society. Hence, participation in HE was seen to have both personal/individual and collective benefits.

My fourth sub-question explores the life experiences of inclusion or exclusion of students with albinism in different phases of education and in their interaction with HE opportunities.

The experiences of 14 students with the condition in all phases of education show that teaching methodologies and teaching and learning tools were often not conducive to their successful learning as they excluded them from the learning processes. The findings further show that the teaching methodologies applied by teaching staff, teaching skills and the teaching and learning tools were not in line with the specific learning needs of students with albinism. Such exclusion is clearly seen in the experiences of the 14 students with the condition who some of them had to devise their own ways of interacting with education. Some opted for rote learning, discussions and some like Happiness decided to concentrate on five subjects. Thus revealing that students with albinism were often excluded in all phases of the education.

Again, the learning environments, as indicated by participants in this research, were not conducive for the learning of students with albinism as they were designed with specific 'ideal' students in mind and students with the condition were not included thus portraying the existence of a medical model in the four institutions of my research site as well as in the five universities where the graduate with albinism in this research had graduated. The existence of the medical model means that students with albinism are required to adapt to the practices and the environment of universities rather than universities having to adjust to include them in their practices. Thus, inclusion in HE was seen to omit societal, environmental and impairment issues that impact on the lives of students with albinism (Shakespeare, 2014).

My fifth sub-question looks at the HE academic experiences in terms of teaching and learning, assessment and learning support. In relation to teaching and learning the 14 students with albinism experienced HE as stressful, humiliating and frustrating. The stressful teaching and learning experiences are demonstrated by the 14 students with albinism particularly Deborah and Thomas, who often invested long hours in copying notes after classes, thus having limited time to write assignments or prepare for examinations. But were never given extra time to submit their assignments which often raised their anxiety and fear of failing examinations as clearly demonstrated by Happiness, David, Meshack, Sarah, Deborah and Lucas who frequently felt they would fail their examinations. Thus showing that academic experiences of students with albinism in terms of assessment were often stressful.

In addition to experiencing HE academics as stressful, students with albinism also demonstrate a frustrating academic experience. Such experiences are clearly revealed by Happiness who had to frequently go to the blackboard to see what was written on the board and instead of being supported she was seen as naughty and a pretender. Likewise such experiences are also seen in David's reflection about Martha whose examination paper was destroyed after she had demanded to be supported by being given examinations in enlarged font. More so frustration and humiliation is also evident in Loveness' academic experiences after she was thrown out of the lecture room in the presence of her fellow students only because she could not respond to a call made by her HE teacher.

Exploring further the academic experiences of students with albinism, my findings reveal that HE was gendered as it was experienced differently by women with albinism and men with albinism. Loveness, Happiness, Sarah and David who talked about Martha, for example, demonstrate these differences. Loveness, Sarah and Martha as women experienced HE as humiliating after being harassed by male teaching staff. As for Happiness she experienced it as oppressive when she was seen as a passive person and a liar for revealing that she could not see clearly what was written on the board.

My sixth sub-question looks at what specific support was in place for students with albinism. As already mentioned, students with the condition widely suffer from low vision, the hot and sunny tropical climate, and hate crimes including attacks and murder threats. In this case, their specific support is expected to focus on these areas through the provision of appropriate devices or services to support such needs. But my findings, as demonstrated by the 14 students with albinism, show that none of them were provided with appropriate devices or services to support their specific learning. Thus revealing that in addition to excluding students with albinism, HE participation further marginalised them.

Nevertheless students with albinism were sometimes provided with readers. Grace, Sarah and Thomas who had readers, acknowledged their contribution in learning, however they challenged the appointment of fellow students as readers. To them students often had assignments and examinations to prepare for therefore they could not adequately provide the support that students with the condition often needed. In this context, my findings reveal that although the appointment of students as readers had social benefits as

it allowed students with albinism to have friends, academically it had a negative impact, as student readers could not adequately support the learning of students with albinism given the workload that they often had as reflected by Mary.

Given the security threat that people with albinism often experience, the support that the 14 students with albinism mentioned and valued was the provision of accommodation that universities often assured disabled students including students with the condition. As we often protect and secure what we value and hold with high esteem, my findings reveal that the assurance of university accommodation to students with albinism did not only assure them safety and security but also gave them a sense of inclusion and value. Thus promoting a positive academic attitude seen in the 14 students with albinism.

Having discussed my research questions in relation to my findings and existing literature, I now turn to make the main contribution of this research.

7.4 Main contributions of my research

The main contributions of my thesis are in four major areas:

- Firstly, my feminist approach has included gendered aspects of albinism that have not been explored in any detail in previous studies.
- Secondly, studies of albinism in education have often focused on participation/exclusion from basic level education which is pre-higher education (Lynch & Lund, 2011). My thesis thus contributes to knowledge of albinism in HE.
- Thirdly, people with albinism are often represented in terms of their victimhood, which is as passive victims without agency. Drawing upon the concept of agency, my thesis removes albinism from sticky victimhood and begins to associate it with extraordinary agency.
- Lastly, by removing albinism from purely the victimhood perspective and showing that people with albinism are active human beings struggling, and negotiating their way even into HE, valuable information is provided on what needs to change. Therefore, I present my recommendations below. These recommendations are in line with my seventh sub-question, which explores what needs to be done differently to enhance the participation and achievement of students with albinism in Tanzanian HE.

7.5 My recommendations

My study has highlighted some issues that require further investigation by schools, both primary and secondary, HE institutions and government policy-makers. Various interrelated factors have been mentioned that influence the interaction of students with albinism with HE opportunities, some of which contribute to the enduring underrepresentation of students with albinism in HE. The complexity of the issues that were raised in this research does not allow for simple solutions. However, solutions can be sought that will change and remove the social and cultural structures that limit the opportunities and agency of students with albinism to interact with HE. Therefore, the findings of this study have implications at national, institutional and family level. For this reason, I recommend actions that might be taken at all levels and in my concluding remarks I emphasise the importance of the removal of social and cultural constraints, such as beliefs in witchcraft and superstitions, and the reinforcement of enablers such as parental and teachers' support systems. The recommendations I make also incorporate the suggestions by participants in this research, including the fourteen students with albinism and, thus, answer my seventh sub-question regarding their messages to universities, the Tanzanian people or the government of Tanzania about students and people with albinism.

7.5.1 Recommended interventions at government level

As already mentioned, various issues emerge, such as the exclusion of people with albinism and poverty, which require the action of government policy-makers. I therefore itemise these actions below.

7.5.1.1 Establishing early intervention programmes

The exclusion of students with albinism from educational participation starts early on, in their primary and secondary education. Therefore, if there is going to be an adequate pool of students able to enter HE, interventions need to start early in their lives. Early intervention programmes targeting support for parents and teachers in the early life of children with albinism should be given priority by the government, and funds should be set aside for this purpose.

As revealed in this thesis, children with albinism are sometimes traumatised not only by the surrounding community but also by parents or family members. This means that, when

growing up, they need a positive upbringing from both fathers and mothers for a positive adulthood. Support for parents and awareness campaign programmes should therefore target the minimisation of the stigmatisation and oppression of people with albinism and should also include the minimisation of witchcraft beliefs and superstitious beliefs, and beliefs about mothers of children with albinism. There should also be awareness and counselling programmes for both mothers and fathers. Parents need to be empowered through awareness and support programmes, which can lead to the better management of their children. Such programmes can be initiated by NGOs with the financial support of the government. Four officials from the two NGOs that participated in this research talked about having very limited financial support from the government and, thus, having limited funds to adequately implement awareness and advocacy programmes. Given the necessity of such programmes, the government should allocate adequate funds to finance NGOs responsible for the welfare of people with albinism.

My study has revealed the significant role that parents play in improving the participation of students with albinism in HE. However, the study has also indicated that parents can hide or reject their children with albinism because of poverty or shame, or can discriminate against their own children. Countries such as the UK, USA, Canada and Australia have had early intervention programmes like Sure Start, Head-start and the Early Years Plan which aim to provide disadvantaged children with the best start in life through health and family support, childcare services and early education, (Carpenter, 1997; Tunstill and Allnock, 2007). Of course, such programmes require a huge amount of resources and time, which a developing country like Tanzania may not have the means to finance. However, given the life experiences that people with albinism and their families often endure, and the aim of the programmes, which is to break the intergenerational transmission of poverty, it would be worthwhile for the government of Tanzania to invest in programmes similar to Sure Start in the UK specifically for families with children with albinism, which might not cost much and could be viewed as an important investment as their education will help to include them in the labour market. This is because such programmes in the Global North have reported positive outcomes in the lives of children and adults who were involved in them (Carpenter et al., 2005).

Although Tunstill and Allnock (2007) suggest that at present we cannot determine the ultimate effectiveness of the UK Sure Start Local programmes, their study reveals that

the impact of the programmes on nine thousand three-year-olds and their families in one hundred and fifty such programmes was beneficial. The study observed that disadvantaged children and families under the Sure Start programmes were benefiting as compared to disadvantaged groups who were not involved in the programmes. For example, mothers involved in Sure Start programmes were found to experience fewer household disputes than those outside the programmes. Likewise, young mothers of three-year-olds under the Sure Start Local programmes were found to be engaged in less negative parenting than those not in the programmes.

It is also likely that programmes such as Sure Start in Tanzania will be beneficial to children and families of children with albinism, particularly mothers, as they can lessen the household chaos often experienced by such mothers. Given that Sure Start Local programmes are often tailored to local needs (Tunstill and Allnock, 2008) Tanzania can adopt such programmes and customise them to local needs. The programmes should aim to enhance the living standards of children and families with children with albinism so as to enable people with albinism to adequately participate in social services such as education and, thus, promote social cohesion among Tanzanians.

Intervention in the early lives of children with albinism should also target teachers at all phases of the education ladder. National policies should be established which direct the integration of special needs education programmes into teacher training so that student-teachers at different phases of education become aware of the varying needs of learners with albinism.

7.5.1.2 Enhancing poverty-eradication programmes

Literature indicates that poverty is one of the factors that prompts violence against people with disability (Emerson & Roulstone, 2014). Similarly, poverty was also seen as one of the reasons for the frequent attacks and killing of people with albinism. This means that unless poverty is minimised, the attacks, killing and mistreatment of people with albinism will be difficult to overcome. Minimising poverty will require the strengthening of poverty-eradication programmes such as MKUKUTA, the Kiswahili acronym from the translation of National Strategy for Growth and Reduction of Poverty. Such programmes need to reach the grassroots, particularly in rural areas. There is a need for national policy-

makers to ensure that MKUKUTA programmes are widespread in areas where killings of people with albinism are high, like the Lake Zone area.

The link between poverty and disability is recognised (Coleridge, 1993; Filmer, 2009; Groce et al., 2011). I have shown in my introductory chapter that people with albinism often live in poverty. The potential of HE to minimise poverty is well-documented and known (see Brennan & Durazzi, 2013; Bloom et al., 2006). Given that HE has the potential to minimise poverty (Brennan & Durazzi, 2013; Bloom et al., 2006) and that poverty was seen as one of the factors that constrained the participation of students with albinism in HE, without proper efforts to financially enable them, many will not be able to attend, or be retained in, universities. It is important that students with albinism are provided with financial support by the government, such as bursaries or scholarships, in order for them to access the opportunities that HE offers. This means that the government should establish grants for disabled students, including those with albinism, similar to those provided to students undertaking the Doctor of Medicine degree programme, as explained in section 1.8.

7.5.1.3 Establishing programmes to reduce prejudice

McBride (2015), who examined effective ways to tackle prejudice and discrimination by drawing upon UK and international studies in various settings, says tackling prejudice and discrimination was not an easy task as it was difficult to measure attitudes. However, McBride (2015) suggests two theories as to how to reduce prejudice. The first is the intergroup contact theory and the second focuses on providing information about the discriminated groups. The former theory, according to McBride (2015), emphasises bringing the discriminated and discriminating groups together so as to promote inclusivity and consequently reduce negative attitudes. The latter holds that contact alone is not adequate to change people's attitudes and thus suggests that people also need to be educated and re-educated to change their deeply ingrained prejudicial attitudes.

Although the theory of intergroup contact through schools, universities and workplaces between people with albinism and those without would allow the establishment of a relationship, the mistreatment of people with albinism, as revealed in this study, is also circulated through witchcraft and superstitious beliefs brought about by a lack of awareness about albinism. Drawing upon a theory which focuses on providing positive

information about people with albinism would thus minimise this lack of awareness and, consequently, promote a better understanding of albinism. Tanzania has reported positive and encouraging stories about its HIV/AIDS education and campaign programmes. Due to successful campaign programmes which drew upon the theory of providing information and included advocacy, changes in general behaviour, changes in communication and reduced prejudice the rate of HIV/AIDS cases has drastically declined, as has prejudice against HIV/AIDS sufferers (Tanzanian Commission for AIDS (TCAIDS), 2015).

Positive outcomes for HIV/AIDS intervention programmes were due to the joint efforts of the media, non-governmental organisations, the government and society at large. Various campaigns and awareness methods were used to pass on the message and change society's mind-set. National policy-makers should design similar strategies to address witchcraft and superstitious beliefs as well as the prejudice that is attached to albinism so as to reduce hate crimes. In addition to awareness programmes, the strategies should also aim at strengthening intergroup contacts between people with albinism and those without in schools, universities and communities. The government should ensure there are policies against discrimination in schools and universities, and that these are abided by. Follow-up mechanisms should be established whereby schools and HE institutions should be required to submit reports on how such policies are implemented.

7.5.2 Recommended interventions at HE institution level

Other issues which emerge in this research also need to be addressed by HE institutions.

7.5.2.1 Improving teaching skills

Given that most teaching staff in HE in my study were employed from a pool of students with limited teaching skills or professional training and development, there is a need to provide HE teaching staff with training and skills for the proper teaching of students with special needs, including those with albinism. The need for such training was observed from the six teachers whom I interviewed, as five of them reported clearly that they had never received any such training and were overwhelmingly interested in doing so. They felt that such training and skills would enable them to effectively teach students with albinism. Universities in Tanzania should have policies which require their teaching staff to have skills to teach disabled students, including those with low vision.

7.5.2.2 *Improving HE practices*

Problems relating to academic assessment as reflected upon by Sarah, Happiness, Meshack, Isaack and Martha (mentioned by David) appeared to affect the smooth participation of students with albinism in HE. In this case, there is a need for HE institutions to adopt a system that will overcome the possibilities of favouritism or victimisation of students. From the experiences of other universities, particularly those in the Global North, a system of external examiners would be ideal to minimise the possibilities of violations of fair assessment. Given the cost involved and the limited funds often allocated to institutions, some universities, like the University of Dar es Salaam, have opted for a system of using external examiners every two to three years (Materu, 2007). Given the cultural norms and power structures often embedded in HE systems, women in HE are more likely to be targets of sexual harassments (Paludi and Barickman, 1991 cited in Morley, 2011d: 102). Thus victimisation or favouritism in academic assessment can occur anytime and female students are the most affected gender when external examiner systems are absent. Universities should therefore have systems of external examiners, irrespective of the costs involved, because the value of the lives of those women with albinism in this study who were harassed and abused is greater than the cost involved in engaging external examiners. The examinations to be examined should also be prepared in fonts that are friendly to students with albinism.

The desire and commitment of learners with albinism, as well as their dedication to participation in HE, were loud and clear. Such commitment and dedication was a confirmation to both public and private universities in Tanzania that the wishes of students with albinism were to enter HE, and that denying or limiting their admission would thus be blocking their dreams. This means that there is a need for universities to recognise such dreams, and work towards successful programmes to widen participation. Recognising the challenges that a female student often encounters in accessing HE, some universities introduced access programmes which involved pre-entry programmes catering for female students. Institutions should also acknowledge the social and cultural constraints that students with albinism often face in their interaction with HE opportunities and work towards designing access programmes that would allow the entry of these students into HE.

In relation to the inclusion or exclusion of students with albinism in or from HE, Riddell et al. (2005) tell us that few institutions prepare in advance to receive disabled students. This unpreparedness of institutions was also noted in this study, as officials at the students' support unit indicated that they had no prior records of students with albinism until the students turned up at the unit to register. Neither did the teaching staff have prior knowledge of students with albinism in their classes. For purposes of quality assurance, therefore, institutions need to prepare in advance for students with albinism, so as to provide them with a favourable learning environment for their successful participation in HE. Institutions need to know beforehand the number of their expected students with albinism and, because these students are not homogenous, institutions need to know each of their expected students' unique support requirements. The aim here, according to Riddell et al. (2005), should be for major institutional change rather than an emphasis on student support. By knowing beforehand, institutional change could involve teaching styles and ways of circulating information. Teaching style should recognise and adapt to the requirements of all students, irrespective of their differences. The transmission of information in universities should also accommodate students of all differences.

7.5.2.3 Providing conducive teaching and learning environments

Given that there were indications that some teaching and learning materials used in HE were limited and that some of them were excluding students with albinism, there is a need for HE institutions to acquire adequate materials and use teaching and learning materials that are inclusive, such as large print. This means institutions need to tell designers of teaching and learning materials to supply them with teaching materials that can accommodate difference, such as that of students with low vision. HE institutions should, therefore, influence designers to produce teaching and learning materials which can accommodate students' differences so as to facilitate the universal accessibility and usability of such devices.

Looking at the specific support in place for students with albinism, of the four universities that I visited, only one had an established unit to support students with disabilities. This shows a need for universities to establish such services, which should incorporate provision for counselling. Most students with albinism do not only experience challenges posed by poor vision but also emotional challenges, and therefore do not only require support with reading and taking notes, but also counselling, as clearly suggested by the

NGO officials, Ester and Abraham, who participated in this study. Due to the stigma and oppression attached to albinism, and as revealed in some of the literature, students with albinism often experience stress or anxiety (Ezello (1987). As recommended by Elizabeth in my study, there is a need for universities to have counselling support services as well as organising life-skills programmes for students with albinism. The WHO defines life skills as ‘abilities for adaptive and positive behaviour that enable individuals to deal effectively with the demands and challenges of everyday life’ (1993: 1). The WHO lists these skills as decision-making, creative thinking, effective communication, self-awareness, coping with emotions, problem-solving, interpersonal relationships, empathy and coping with stress (1993: 1). Life-skills education, as defined by the WHO, would be useful for the psychological wellbeing of students with albinism as it would equip them with the skills to cope with the stress brought about by the emotions, misogyny, symbolic violence and social and cultural structures that often surround albinism.

7.6 Recommendations for future research

As mentioned in the introduction, albinism affects all ethnic groups and worldwide the frequency rate is one in every 17,000 people. It has also been found that globally, people with albinism experience discrimination and bio-pyscho-social challenges. However, little is known about the experiences of people with albinism in some countries. There is therefore a need for more in-depth social studies on albinism and the experiences of those with the condition. This means that more studies are needed on albinism and HE from African countries as well as other parts of the world.

Given that high incidences of albinism are notable among the Native American Kuna and Zuni in Panama as well as people in the Dominican Republic and Japan (NOAH, 2002), it would be interesting to have an in-depth study to compare and contrast with the present one. It would also be interesting to have in-depth information on the educational experiences of people with albinism from these parts of the world.

Given that Burstall (2012) indicates that people with albinism in the UK and other parts of the Global North sometimes experience unfriendly stares and name-calling, and given that no research that I know of in this part of the world has directly focused on people with albinism or their experiences, or the constraints on or support for their participation

in different phases of education, it would be useful to have a study that does so. Such research would provide us with knowledge as to whether people with albinism in the UK or the Global North, where there is advanced technological development, have similar experiences to those who participated in this research. It would also be interesting to know the experiences of students with albinism in an educational environment which has better teaching and learning facilities and support services than those of Tanzania.

Unlike Tanzania, some countries do not consider albinism as a disability. For this reason, albinism has attracted limited research compared to other disabilities such as visual or hearing impairment, reduced mobility or any other human impairment. As mentioned in the introduction, the UN Convention 61/106 (2006) defines disabled people as those who have barriers that may affect their equal participation in society. Going by such a definition, research on albinism in the Global North would provide us with an understanding as to whether albinism in these countries qualifies to be categorised as a disability. Furthermore, it would also be interesting to explore how HE benefits those with albinism in Tanzania in terms of employment prospects.

7.7 Epilogue

When analysing the structures and agency of the social lives of students with albinism in Chapter Six, it was revealed that other disabled students were treated better than students with albinism; in particular, supportive devices such as braille or hearing aids as well as interpretation services were provided to students with visual or hearing impairments, whereas students with the condition were often not provided with their specific devices: namely, magnifiers or monoculars. Sarah, a student with albinism who had performed poorly in some of her courses because of lack of adequate support, has the final words.

(e)ducational institutions should consider students with albinism just like other students and they should give them their specific needs. For example, in other places if you have a disability you cannot go to school because the environment is not conducive. I think institutions should recognise that there are people with albinism which is like any other disability. The difference which exists, is very minor and institutions should support students with albinism to achieve their goals. Institutions should provide a good learning environment. A student with albinism needs to be educated like any other student. There should not be any stigmatisation in schools, HE or in society. Also, people should be made aware about albinism.

Just imagine, I am at university but to date some students cannot even come near me. When they are made aware I think there will be no problem: they will know I am a human being. For the government, it should protect people with albinism. We have been hearing about the killings. I hear that there are court cases about the killings but I don't think any ruling has been made. That is why the killings are continuing. I think the government should look more into this. (Sarah, female student with albinism- LSES).

Sarah's message is for Tanzanians to recognise and respect peoples' differences. The same message is directed to universities, where she advises them to provide specific support to students with albinism so that they can adequately interact with HE opportunities.

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Appendix 1: Vignette of my 35 participants

Sarah

Sarah is a female student with albinism with an age range of 26-36 years old. She is an undergraduate student undertaking a degree programme in a subject area of law and social sciences. Sarah was rejected by her father and was therefore, brought up by her mother and grandmother. Sarah is a first generation HE student as her mother who is self employed with irregular income was a primary school leaver before she enrolled herself for secondary education as a way of motivating her daughter to continue with education. Sarah succeeded to join HE after re-sitting her 'O' level examination and progressed to 'A' level education consequently to HE. Sarah has one young sibling who is without albinism. She also has a child who she takes care of singularly.

Grace

Grace is female student with albinism with an age range of 17-25 years old. She is an undergraduate student undertaking a degree programme in a subject area of business, management and administration. Grace was brought up by both her parents. She is a first-generation HE student as both her parents are primary school leavers who live in a rural area. Grace was motivated by her teachers to aspire for HE and she progressed to HE after obtaining excellent examination results in both her 'O' and 'A' level education. She has five siblings and one of them has albinism.

Thomas

Thomas is male student with albinism with an age range of 37-47 years old. He is a postgraduate student undertaking a degree programme in a subject area of education in arts. Thomas was brought up by both his parents before they passed away when he was in primary school education. Both his parents had non-degree profession training and were employed therefore had regular income. Thomas is a first generation student and was supported by a religious body to progress with his education consequently into HE after obtaining excellent examination results in both his 'O' and 'A' level education. Thomas has four siblings and he is the only one with albinism. Thomas has a partner and a child.

Angel

Angel is female student with albinism with an age range of 17-25 years old. She is an undergraduate student undertaking a degree programme in a subject area of law and social sciences. Angel was rejected by her father and was therefore brought up by her aunty. Angel's mother has no formal education and she is self-employed with irregular income. Angel is a first-generation student and to progress to HE she had to re-sit for her 'O' and 'A' level education. Angel has three siblings and she is the only one with albinism. She is also a first-generation student.

Simon

Simon is male student with albinism with an age range of 37-47 years old. He is an undergraduate student undertaking a degree programme in a subject area of education in arts. Simon was brought up by both parents. Both his parents have informal education and they lived in a rural area. Simon is a first-generation student and he progressed to HE after he was, motivated by his teachers and friends. Simon has five siblings and he was the only one with albinism. He has a partner and children.

Loveness

Loveness is female student with albinism with an age range of 17-25 years old. She is an undergraduate student undertaking a degree programme in a subject area of medical science. Loveness was brought up by both parents. Her father has HE qualifications with formal employment and a regular income while her mother has primary school education. Loveness was motivated by her mother to proceed with her education and consequently entered HE. Loveness has two siblings and she is the only one with albinism.

John

John is male student with albinism with an age range of 37-47 years old. He is a postgraduate student undertaking a degree programme in the subject area of law and social sciences. John was brought up by his mother and father. His mother has degree qualifications with formal employment. His father has non-degree qualifications and he also has formal employment. Both John's parents have regular incomes. John was motivated by his mother to proceed with education and consequently HE. He has two siblings and one of them had albinism.

Meshack

Meshack is male graduate with albinism with an age range of 26-36 years old. He graduated with a degree in a subject area of education science. Meshack was brought up by both parents. Both his parents have primary school education but with formal employment and regular income. Meshack is a first-generation student and he progressed to HE after he was, motivated by both his parents and friends. Meshack has two siblings and he was the only one with albinism. He is in formal employment and has regular income.

Happiness

Happiness is female graduate with albinism with an age range of 26-36 years old. She graduated with a degree in a subject area of law and social sciences. Happiness was rejected by her father and was therefore brought up by her grandmother and mother. Her mother who lives in the rural area has no formal education and she is self-employed with irregular income. Happiness is a first generation student and she progressed to HE after she was, motivated by some people in her community. Happiness has five siblings and one of them who they share the same father has albinism. She is in formal employment and has regular income.

David

David is male graduate with albinism with an age range of 26-36 years old. He graduated with a degree in a subject area of law and social sciences. David was rejected by his father and was therefore brought up by his mother and uncle. His mother who has primary school education is employed in a minimum income job. David is a first generation student and he progressed to HE after he was, motivated by his mother. David has one sibling without albinism. He is involved in formal employment and has regular income.

Peter

Peter is a male graduate with albinism with an age range of 48-58 years old. He graduated with a degree in a subject area of law and social sciences. Peter was brought up by both parents. Both his parents have neither formal education nor formal employment. Peter is a first-generation student and he progressed to HE after he was, motivated by his teachers and mother. He is engaged in a formal employment and has regular income. Peter has seven siblings and one of them has albinism. Peter has two partners and children.

Isaack

Isaack is a male graduate with albinism with an age range of 37-47 years old. He graduated with a degree in a subject area of law and social sciences. Isaack was brought up by both parents. Both his parents had neither formal education nor formal employment. Isaack is a first-generation student and he progressed to HE after he was, motivated by his young sibling. Isaack has nine siblings and one of them has albinism. He has a partner and children. He is engaged in formal employment and has regular income.

Lucas

Lucas is male graduate with albinism with an age range of 37-47 years old. He graduated with a degree in a subject area of business, management and administration. Lucas was brought up by his mother and father. His father has degree qualifications with formal employment. His mother has non-degree qualifications but she was formally employed. Lucas was motivated by his parents and elder siblings to proceed with education and consequently HE. He has seven siblings and none of them has albinism. He has a partner and children. He is engaged in formal employment and has regular income.

Deborah

Deborah is female graduate with albinism with an age range of 26-36 years old. She graduated with a degree in a subject area of law and social sciences. Deborah was brought up by both parents but they pass away before she entered HE. During his life-time Deborah's father had formal employment and non-degree professional education. Her mother was a secondary school leaver and she was formally employed. Deborah was self-inspired to join HE because she wished to be a prominent person in the society. But due to lack of financial support she dropped out of university. Deborah was able to continue with her studies after a sympathiser offered to pay for her studies and her up keep. Deborah has two siblings one of them who they share a father has albinism. She is engaged in formal employment and has regular income.

Joshua

Joshua is male teaching staff with an age range of 48-58 years old. He teaches degree programmes in a subject area of business, management and administration. In his university teaching career he has taught at least two students with albinism. He has

supported them by giving them hand-outs. He has no skills of teaching disabled students and he has received no formal training on how to handle disabled students. Joshua issues handouts not because of his institution policy but because of his own initiatives.

Elizabeth

Elizabeth is female teaching staff with an age range of 59-69 years old. She teaches degree programmes in a subject area of education in arts. In her university teaching career, she had taught at least seven students with albinism. Elizabeth who is a teacher by profession has skills and formal training of teaching and handling disabled students. She had been a secondary school teacher before she began teaching at university. While teaching at secondary school level she taught five students with albinism.

Ruth

Ruth is female teaching staff with an age range of 48-58 years old. She teaches degree programmes in a subject area of education in arts. In her university teaching career she has taught at least four students with albinism. Ruth who is a teacher by profession has skills and formal training of teaching and handling disabled students. She had been a secondary school teacher before she began teaching at university. While teaching at secondary school level she taught five students with albinism.

Steven

Steven is male teaching staff with an age range of 48-58 years old. He teaches degree programmes in a subject area of education in arts. In his university teaching career, he had taught one student with albinism. Steven has no skills or formal training of teaching or handling disabled students.

Yeremia

Yeremia is male teaching staff with an age range of 48-58 years old. He teaches degree programmes in a subject area of education in arts. In his university teaching career he had taught two students with albinism. Yeremia has no skills or formal training of teaching or handling disabled students. He supported the students with albinism in his class basing on his own efforts.

Azaria

Azaria is female teaching staff with an age range of 48-58 years old. She teaches degree programmes in a subject area of education in arts. In her university teaching career, she had taught one student with albinism. Azaria who is a teacher by profession has no skills and formal training of teaching disabled students. She had been a primary school teacher before she began teaching at university. While teaching at primary school level she taught one student with albinism.

James

James is a support staff with an age range of 37-47 years old. He has been working at the support unit for almost four years. His speciality is supporting students with hearing impairment. He is trained at degree level.

Paul

Paul is a support staff with an age range of 48-58 years old. He has been working at the support unit for almost six years. His speciality is supporting students with vision impairment. He is trained at degree level.

Titus

Titus is a support staff with an age range of 48-58 years old. He has been working at the support unit for almost five years. His speciality is supporting students with vision impairment. He is trained at degree level.

Timothy

Timothy is a support staff with an age range of 48-58 years old. He has been working at the support unit for almost seven years. His speciality is supporting students with vision impairment. He is trained at degree level.

Julius

Julius is a support staff with an age range of 37-47 years old. He has been working at the support unit for less than a month. He has no specific speciality in supporting disabled students. He is trained at degree level.

Ester

Ester is a female NGO official with an age range of 48-58 years old. She has been working for the NGO responsible for the welfare of people with albinism for almost seven years. She does not have albinism.

Abraham

Abraham is a male NGO official with an age range of 48-58 years old. He has been working for the NGO responsible for the welfare of people with albinism for almost five years. He has albinism.

Michael

Michael is a male NGO official with an age range of 37-47 years old. He has been working for the NGO responsible for the welfare of people with albinism for almost two years. He does not have albinism.

Philemon

Philemon is a male NGO official with an age range of 48-58 years old. He has been working for the NGO responsible for the welfare of people with albinism for almost 35 years. He has albinism.

Eliza

Eliza is a mother of two children with albinism. She has a middle-class economic status. Before she gave birth to her first child with albinism, Eliza says she only had diploma qualifications. However, she says she decided to enrol for a degree programme and later went further, obtaining postgraduate qualifications, because of the challenges she was experiencing as a mother of children with albinism. Eliza says she chose to undertake postgraduate programmes as a way of motivating and encouraging her children with albinism to do the same. Both Eliza's children with albinism have postgraduate qualifications. Eliza and her husband were still living together and had a happy marriage. However, she says her experiences with her in-laws were painful, as at first they rejected her and her children. She says it was only after she obtained HE qualifications and a well-paying job that her in-laws began to accept her and her children.

N.B Information about other five participants is as per table 6 and 7.

Appendix II: Interview Guide- Semi-structured interview for students with albinism

Identification Number	
Gender	
Institution	
Date of interview	

Good morning/afternoon. Thank you for accepting to participate in this research. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. I am keen to explore your experiences of higher education e.g. the support that you received, any difficulties that you encountered etc.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. You are welcome to stop the machine at any point during the interview. The interview will be transcribed and anonymised so that you will not be recognisable to other people. The interview will also be confidential and the recorded material will not be accessible to any other person than myself.

Be assured that I will not use your name in any of my reports or in my PhD thesis. Also you are free to refuse to answer any particular question you do not want to answer. Our discussion will not take more than 60 minutes. You have an option to use English or Kiswahili language. Do I have your permission to use the audio-recorder and to begin our discussion?

Warm up: I would like to start by asking a few factual questions about you:

- What are you studying,
- What year are you in?
- Are you an undergraduate or postgraduate student?

Topic: Family

Q1 Tell me a bit about your family what do they do for a living?

Sub-question:

- What is your parent's level of education? Can you differentiate between your mother and father
- How many of your siblings are attending or have attended HE?
- What is the attitude of your parents towards your HE?
- What is the attitude of your siblings towards your HE?

Topic: Earlier educational experiences

Q2 Do you have any particularly positive/ negative recollections of:

- Your primary school – can you give me some details? Can you recall a specific incident?
- Your secondary school- can you give me some details? Can you recall a specific incident?

Topic: Motivation

Q3 What would you say inspired you to pursue HE?

Sub-question:

- Can you remember how old were you when you decided that you wanted to pursue HE?
- Who encouraged you to enter HE? In what way?
- Did anyone discourage you? In what way?
- What were they concerned about?
- What did you feel about the concerns?

Topic: University entry

Q4 How would you describe your experiences of the admissions' process?

Sub-questions:

- What was it like for you to enter HE?
- Did you have any particular positive experiences?
- Did you have any particular negative experiences?
- What, if anything would you change about the admission process if you could?

Topic: Transition

Q5 What were your first impressions of university life?

Sub question:

- Can you tell me how it felt to become a university student?
- What were your fears and hopes?
- Did you have any particular positive experiences at the outset?
- Did you have any particular negative experiences at the outset?
- What if any would you change about transition to university life?

Topic: Experiences of the course

Q6 Can you tell me what led you to select the course program you are studying?

- What are your positive experiences of your course of study?
- What are the negative experiences of the course?
- What changes, if any, would you like to see?

Topic: Support services

Q7 How would you describe the support that you are receiving?

Sub-questions

- Who are your main forms of support? In what way do they support you?
- How would you describe the support that you have received from the university?
- How would you describe the support that you receive from teaching staff?
- How would you describe the support that you receive from your fellow students?
- What changes, if any, would you like to see in the support that you receive?

Topic: Aspirations

Q8 What are your plans for the future?

Sub-questions:

- What work would you like to do when you graduate?
- What are your long-term goals?
- What support do you need to help you accomplish your goals?

Topic: Policy recommendations

Q9 What messages do you have for policy makers about people with albinism's needs in HE?

Sub-questions:

- What specific messages do you have for universities about students with albinism?
- What messages do you have for Tanzanian people about people with albinism?
- What is your message to the Government about the PEOPLE WITH ALBINISM community?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in my questions?

Appendix III: Focus group discussion schedule for graduates with albinism

1. Welcome and introduction- (3 minutes)

Good morning/afternoon and welcome to our session. Thank you for accepting to join me to discuss about your experiences of HE as graduates with albinism. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. I am keen to explore your experiences of higher education e.g. the support that you received, any difficulties that you encountered as students with albinism when you were in higher education.

2. Guidelines- (4 minutes)

In discussing our questions there are no wrong but rather different opinions. Feel free to share your views even if they differ from others. I am interested to hear both your negative as well as your positive comments.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. The interview will be transcribed and anonymised so that you will all not be recognisable to other people. The discuss will also be confidential and the recorded material will not be accessible to any other person than myself.

I assure you of complete anonymity and confidentiality. In this session we will use our first names. When I come to write up and report our discussion, all names will be changed. Be assured that I will not use any of your names in any of my reports or in my PhD thesis. We will not be telling people outside this room who said what. Therefore, when you have something to say repeat your name each time you speak. This is only to help me to easily connect the comments with the person speaking when I am listening to the recorder. We have a list of questions and we will choose five questions for discussion and we should aim to discuss each question for at least 16 minutes.

We should agree that we should all turn off our mobile phones. However, if for any reason it is necessary that you have your phone on, then when it rings I would be grateful if you would answer it quietly outside this room and rejoin us as quickly as you can.

3. Participants introduction- (3 minutes)

Well, let us begin. My role as a moderator will be to guide the discussion. Our session will not take more than 90 minutes. We all have name badges to help us remember each other's name. Let's have an opening circle in which you tell us your name, your year of graduation and where and what you studied. We have an option to use English or Kiswahili language.

4. Values continuum- questions (80 minutes – around 5 questions for discussion 16 minutes per question)

Q1 What motivated you to want to enter HE?

Sub question:

- Who encouraged you and how
- Has anyone else had similar experiences?

Q2 How would you describe your experiences of entering HE?

Sub questions:

- Could you say some more about that please?

Q3 How would you describe your first impressions of university?

Sub questions:

- Can you recall how it felt to become a university student?
- What were your fears and hopes
- Was this experience similar for others?

Q4 How would you describe the support that you received when you were at university?

Sub questions:

- Could you say some more about that please?
- What do other group members think about that?

Q5 What messages do you have regarding support for making HE more inclusive/ welcoming for people with albinism?

- What are your plans for the future?
- What do others think about that?

Appendix IV: Interview Guide Semi-structured interview for Teaching staff

Identification Number	
Gender	
Institution	
Date of interview	

Good morning/afternoon. Thank you for accepting to participate in this research. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. I have selected you because you hold vital information on the experiences of students with albinism in HE in Tanzania. I am keen to explore their experiences in HE e.g. their teaching and learning experiences, the support that they get, any challenges that they encounter etc.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. You are welcome to stop the machine at any point during the interview. The interview will be transcribed and anonymised so that you will not be recognisable to other people. The interview will also be confidential and the recorded material will not be accessible to any other person than myself.

Be assured that I will not use your name in any of my reports or in my PhD thesis. Also you are free to refuse to answer any particular question you do not want to answer. Our discussion will not take more than 30 minutes. You have an option to use English or Kiswahili language. Do I have your permission to use the audio-recorder and to begin our discussion?

Warm up: Tell me a little about your teaching at this university

- What course program do you teach?
- How long have you been at this university?
- How many albino students have you taught at this university?
- How many albino students are in your course?

Topic: University life

Q1 How would you describe the experiences of students with albinism in this university?

Sub-questions:

- What are students with albinism's particular positive experiences?
- What are their particular negative experiences?
- What changes, if any, would you like to see in their HE experiences?

Topic: Experiences of the course

Q2 How would you describe the experiences of teaching students with albinism?

Sub-questions:

- What teaching and learning needs do you believe that students with albinism face?
- What teaching and learning challenges do you believe that they face?
- What are your positive experiences of teaching students with albinism?
- What are your negative experiences of teaching them?
- What specific training and skills do you have in teaching students with albinism?
- What specific training and skills do you need?
- What changes, if any, would you like to see in the teaching and learning experiences of students with albinism?

Topic: Support services

Q3 How would you describe the support that students with albinism in HE receive?

Sub-questions:

- Who are the main supporters of students with albinism? In what way are they supported?
- How would you describe the support that they receive from teaching staff?
- How would you describe the support that they receive from university?
- What change, if any, would you like to see in the teaching of students with albinism?

Topic: Policy recommendations

Q4 What messages do you have for policy makers about people with albinism's needs in HE?

- What changes, if any, would you like to see in university policies?

- What changes, if any, would you like to see in national policies?
- What messages do you have to universities about people with albinism's needs in HE?
- What is your message to the Government?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in my questions?

Appendix V: Interview guide Focus group for Teaching staff

1. Welcome and introduction- (3 minutes)

Good morning/afternoon and welcome to our session. Thank you for accepting to join me to discuss about your experiences of HE as albino graduates. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. I am keen to explore the experiences of students with albinism in higher education e.g. the support that they received, any difficulties that they encountered as higher education students

2. Guidelines- (4 minutes)

In discussing our questions there are no wrong but rather different opinions. Feel free to share your views even if they differ from others. I am interested to hear both your negative as well as your positive comments.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. The interview will be transcribed and anonymised so that you will all not be recognisable to other people. The discuss will also be confidential and the recorded material will not be accessible to any other person than myself.

I assure you of complete anonymity and confidentiality. In this session we will use our first names. When I come to write up and report our discussion, all names will be changed. Be assured that I will not use any of your names in any of my reports or in my PhD thesis. We will not be telling people outside this room who said what. Therefore, when you have something to say repeat your name each time you speak. This is only to help me to easily connect the comments with the person speaking when I am listening to the recorder. We have a list of questions and we will choose five questions for discussion and we should aim to discuss each question for at least 16 minutes.

We should agree that we should all turn off our mobile phones. However, if for any reason it is necessary that you have your phone on, then when it rings I would be grateful if you would answer it quietly outside this room and rejoin us as quickly as you can.

3. Participants introduction - (3 minutes)

Well, let us begin. My role as a moderator will be to guide the discussion. Our session will not take more than 90 minutes. We all have name badges to help us remember each other's name. Let's have an opening circle in which you tell us about your teaching at this university

- What course program do you teach?
- How long have you been at this university?
- How many students with albinism have you taught at this university?
- How many students with albinism are in your course?

4. Values continuum- questions (80 minutes – around 5 questions for discussion 16 minutes per question)

Q1 How would we describe the experiences of students with albinism in this university?

Sub-questions:

- What are students with albinism's particular positive experiences?
- What are their particular negative experiences?
- What changes, if any, would you like to see in their HE experiences?

Q2 How would you describe the experiences of teaching students with albinism?

Sub-questions:

- What teaching and learning needs do you believe that students with albinism face?
- What teaching and learning challenges do you believe that they face?
- What are your positive experiences of teaching students with albinism?
- What are your negative experiences of teaching them?
- What specific training and skills do you have in teaching students with albinism?
- What specific training and skills do you need?
- What changes, if any, would you like to see in the teaching and learning experiences of students with albinism?

Q3 How would you describe the support that students with albinism in HE receive?

Sub-questions:

- Who are the main supporters of students with albinism? In what way are they supported?
- How would you describe the support that they receive from teaching staff?
- How would you describe the support that they receive from university?
- What change, if any, would you like to see in the teaching of students with albinism?

Q4 What messages do you have for policy makers about people with albinism's needs in HE?

Sub-questions:

- What changes, if any, would you like to see in university policies?
- What changes, if any, would you like to see in national policies?
- What messages do you have to universities about people with albinism's needs in HE?
- What is your message to the Government?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in our discussion?

Appendix VI: Interview guide focus group for Support staff

1. Welcome and introduction- (3 minutes)

Good morning/afternoon and welcome to our session. Thank you for accepting to join me to discuss about your experiences of HE as albino graduates. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. I am keen to explore the experiences of students with albinism in higher education e.g. the support that they received, any difficulties that they encountered as higher education students

2. Guidelines- (4 minutes)

In discussing our questions there are no wrong but rather different opinions. Feel free to share your views even if they differ from others. I am interested to hear both your negative as well as your positive comments.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. The interview will be transcribed and anonymised so that you will all not be recognisable to other people. The discuss will also be confidential and the recorded material will not be accessible to any other person than myself.

I assure you of complete anonymity and confidentiality. In this session we will use our first names. When I come to write up and report our discussion, all names will be changed. Be assured that I will not use any of your names in any of my reports or in my PhD thesis. We will not be telling people outside this room who said what. Therefore, when you have something to say repeat your name each time you speak. This is only to help me to easily connect the comments with the person speaking when I am listening to the recorder. We have a list of questions and we will choose five questions for discussion and we should aim to discuss each question for at least 16 minutes.

We should agree that we should all turn off our mobile phones. However, if for any reason it is necessary that you have your phone on, then when it rings I would be grateful if you would answer it quietly outside this room and rejoin us as quickly as you can.

3. Participants introduction- (3 minutes)

Well, let us begin. My role as a moderator will be to guide the discussion. Our session will not take more than 90 minutes. We all have name badges to help us remember each other's name. Let's have an opening circle in which you tell us your name and your support services at this university.

- How long have you been working as a support staff at this university?
- How many students with albinism are enrolled at this university?

4. Values continuum- questions (80 minutes – around 5 questions for discussion 16 minutes per question)

Q1 How would we describe the experiences of students with albinism in this university?

Sub-questions:

- What are students with albinism's particular positive experiences?
- What are their particular negative experiences?
- What changes, if any, would you like to see in their HE experiences?

Q2 How would we describe the experiences of supporting albino students?

Sub-questions:

- Who are the main supporters of students with albinism? In what way are they supported?
- What specific support needs do students with albinism have?
- How would you describe the support that they receive from university?
- What are your positive experiences of supporting students with albinism?
- What are your negative experiences of supporting them?
- What specific training and skills do you have in supporting students with albinism?
- What specific training and skills do you need?
- What changes, if any, would you like to see in supporting students with albinism?

Q3 What messages do we have for policy makers about people with albinism's needs in HE?

Sub-questions:

- What changes, if any, would you like to see in university policies?
- What changes, if any, would you like to see in national policies?
- What messages do you have to universities about people with albinism's needs in HE?
- What is your message to the Government?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in our discussion?

Appendix VII: Interview Guide-Semi-structured interview for Non-Governmental officials

Identification Number	
Gender	
Institution	
Date of interview	

Good morning/afternoon. Thank you for accepting to participate in this research. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. You have been selected because you hold important information on the formulation and implementation of policies on people with albinism in Tanzania. I am keen to explore the experiences of students with albinism in HE e.g. the support that they get, any challenges that they encountered etc.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. You are welcome to stop the machine at any point during the interview. The interview will be transcribed and anonymised so that you will not be recognisable to other people. The interview will also be confidential and the recorded material will not be accessible to any other person than myself.

Be assured that I will not use your name in any of my reports or in my PhD thesis. Also you are free to refuse to answer any particular question you do not want to answer. Our discussion will not take more than 30 minutes. You have an option to use English or Kiswahili language. Do I have your permission to use the audio-recorder and to begin our discussion?

Warm up:

- How long have you been responsible for the welfare of people with albinism?
- What is the population of people with albinism in Tanzania?

Topic: University life

Q1 What are the main issues that students with albinism face when in HE?

Sub-questions:

- What do you believe are their positive experiences in HE?
- What do you believe are their negative experiences in HE?

Topic: Support services

Q2 How would you describe the experiences of support services to students with albinism in HE?

Sub-questions:

- Who are the main supporters of students with albinism?
- In what way are they supported?
- How would you describe the support that they receive from your NGO?
- What are your positive experiences of providing support services to students with albinism ?
- What are your negative experiences of providing support services?
- What changes, if any, would you like to see in the support of students with albinism?

Topic: Policy recommendation

Q3 How would you describe the policies that address disability in Tanzania?

Sub-questions:

- What policies are specific for students with albinism?
- How do they relate to the education of students with albinism?
- How would you describe the implementation of such policies on the education of students with albinism in HE?
- What changes, if any, would you like to see in HE policies?
- What changes, if any, would you like to see in national policies?
- What is your message to universities about students with albinism?
- What is your message to Tanzanian people?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in my questions?

Appendix VIII: Interview Guide-Semi-structured interview for Government officials

Identification Number	
Gender	
Institution	
Date of interview	

Good morning/afternoon. Thank you for accepting to participate in this research. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. You have been selected because you hold important information on the formulation and implementation of policies on students with albinism in Tanzania. I am keen to explore the experiences of students with albinism in HE e.g. the support that they get, any challenges that they encountered etc.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. You are welcome to stop the machine at any point during the interview. The interview will be transcribed and anonymised so that you will not be recognisable to other people. The interview will also be confidential and the recorded material will not be accessible to any other person than myself.

Be assured that I will not use your name in any of my reports or in my PhD thesis. Also you are free to refuse to answer any particular question you do not want to answer. Our discussion will not take more than 30 minutes. You have an option to use English or Kiswahili language. Do I have your permission to use the audio-recorder and to begin our discussion?

Warm up:

- How long have you been responsible for the coordination of issues concerning disabled people including albino people?
- What is the population of people with albinism in Tanzania?

Topic: University life

Q1 What are the main issues that students with albinism face when in HE?

Sub-questions:

- What do you believe are their positive experiences in HE?
- What do you believe are their negative experiences in HE?

Topic: Support services

Q2 How would you describe the experiences of support services to students with albinism in HE?

Sub-questions:

- Who are the main supporters of students with albinism?
- In what way are they supported?
- How would you describe the support that they receive from the government?
- What are your positive experiences of providing support services to students with albinism?
- What are your negative experiences of providing support services?
- What changes, if any, would you like to see in the support of students with albinism?

Topic: Policy recommendation

Q3 How would you describe the policies that address disability in Tanzania?

Sub-questions:

- What policies are specific for people with albinism?
- How do they relate to the education of students with albinism?
- How would you describe the implementation of such policies on the education of students with albinism in HE?
- What changes, if any, would you like to see in HE policies?
- What changes, if any, would you like to see in national policies?
- What is your message to universities about students with albinism?
- What is your message to Tanzanian people?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in my questions?

Appendix IX: Interview guide-semi-structured interview for Parents

Identification Number	
Gender	
Institution	
Date of interview	

Good morning/afternoon. Thank you for accepting to participate in this research. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. You have been selected to participate in this research because you are in a good position to provide information on the support services received by students with albinism in your university. I am keen to explore the experiences of students with albinism in HE e.g. the support that they get, any challenges that they encountered etc.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. You are welcome to stop the machine at any point during the interview. The interview will be transcribed and anonymised so that you will not be recognisable to other people. The interview will also be confidential and the recorded material will not be accessible to any other person than myself.

Be assured that I will not use your name in any of my reports or in my PhD thesis. Also you are free to refuse to answer any particular question you do not want to answer. Our discussion will not take more than 30 minutes. You have an option to use English or Kiswahili language. Do I have your permission to use the audio-recorder and to begin our discussion?

Warm up: Tell me a little about your experience as a mother of children with albinism.

- How many children do you have?
- How many have albinism?

Topic: Home life

Q1 How would you describe the experiences of children with albinism at home?

Topic: University life

Q1 How would you describe the experiences of students with albinism in all phases of education?

Sub-questions:

- What are students with albinism 's particular positive experiences?
- What are their particular negative experiences?
- What changes, if any, would you like to see in their HE experiences?

Topic: Support services

Q2: How would you describe the experiences of supporting students with albinism?

- Who are the main supporters of students with albinism?
- In what way are they supported?
- What specific support needs do students with albinism have?
- How would you describe the support that they receive from university?
- What are your positive experiences of supporting students with albinism?
- What are your negative experiences of supporting them?
- What changes, if any, would you like to see in supporting albinism?

Topic: Policy recommendations

Q4 What messages do you have for policy makers about people with albinism's needs in HE?

Sub-questions:

- What changes, if any, would you like to see in university policies?
- What changes, if any, would you like to see in national policies?
- What messages do you have to universities about people with albinism's needs in HE?
- What is your message to the government?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in my questions?

Appendix X: Interview guide semi-structured interview for Student Reader

Identification Number	
Gender	
Institution	
Date of interview	

Good morning/afternoon. Thank you for accepting to participate in this research. As I mentioned in my letter, my name is Rose Kiishweko. I am a Tanzanian PhD student at the University of Sussex in the United Kingdom. I am conducting research on *Albinism in Higher Education in Tanzania: A Case Study*. You have been selected to participate in this research because you are in a good position to provide information on the support services received by students with albinism in your university. I am keen to explore the experiences of students with albinism in HE e.g. the support that they get, any challenges that they encountered etc.

I would be grateful if you would permit me to tape record our session, as this will assist me to capture all your insights and observations. You are welcome to stop the machine at any point during the interview. The interview will be transcribed and anonymised so that you will not be recognisable to other people. The interview will also be confidential and the recorded material will not be accessible to any other person than myself.

Be assured that I will not use your name in any of my reports or in my PhD thesis. Also you are free to refuse to answer any particular question you do not want to answer. Our discussion will not take more than 30 minutes. You have an option to use English or Kiswahili language. Do I have your permission to use the audio-recorder and to begin our discussion?

Warm up: Tell me a little about your support services at this university.

- How long have you been working as a student reader at this university?
- How many students with albinism have you supported?

Topic: University life

Q1 How would you describe the experiences of students with albinism in this university?

Sub-questions:

- What are students with albinism's particular positive experiences?
- What are their particular negative experiences?
- What changes, if any, would you like to see in their HE experiences?

Topic: Support services

Q2 How would you describe the experiences of supporting albino students with albinism?

Sub-questions:

- Who are the main supporters of students with albinism? In what way are they supported?
- What specific support needs do students with albinism have?
- How would you describe the support that they receive from university?
- What are your positive experiences of supporting students with albinism?
- What are your negative experiences of supporting them?
- What specific training and skills do you have as a students' reader?
- What specific training and skills do you need?
- What changes, if any, would you like to see in supporting students with albinism?

Topic: Policy recommendations

Q3 What messages do you have for policy makers about people with albinism's needs in HE?

Sub-questions:

- What changes, if any, would you like to see in university policies?
- What changes, if any, would you like to see in national policies?
- What messages do you have to universities about people with albinism's needs in HE?
- What is your message to the Government?

Conclusion of interview

Are there any other areas that you would like to comment on, that have not been covered in my questions?

Appendix XI: Consent Form



University of Sussex

CONSENT FORM FOR PROJECT PARTICIPANTS

Project title: Albinism in Higher Education in Tanzania: A Case Study
Project Approval Reference: ER/RK247/1

I agree to take part in the above University of Sussex research project. I have had the project explained to me and I have read and understood the Information Sheet, which I may keep for records. I understand that agreeing to take part means that I am willing to:

- Be interviewed by the researcher
- Allow the interview to be audio taped
- Make myself available for a further interview should that be required.

I understand that any information I provide is confidential, and that no information that I disclose will lead to the identification of any individual in the reports on the project, either by the researcher or by any other party.

I understand that data will be anonymised to prevent my identity from being made public.

I understand that confidentiality cannot be guaranteed for information which I might disclose in the focus group/s / group interviews.

I understand that my participation is voluntary, that I can choose not to participate in part or all of the project, and that I can withdraw at any stage of the project without being penalised or disadvantaged in any way.

I consent to the processing of my personal information for the purposes of this research study. I understand that such information will be treated as strictly confidential and handled in accordance with the Data Protection Act 1998.

Name:.....

Signature:.....

Email:.....

Telephone:.....

Address:.....

Date:.....

Appendix XII: Example of information sheet for Students

Dear Participant,

RE: Invitation to participate in a research project titled: Albinism in Higher Education in Tanzania: A Case Study.

You are invited to take part in a research study on Albinism in Higher Education in Tanzania: A Case Study. This research is part of the PhD thesis at the University of Sussex in the United Kingdom. I would like us to discuss about your views on interacting with HE opportunities in Tanzania.

What should you do before deciding to participate in the study?

Before you decide whether to participate in the study it is important that you understand what this research is for and what you will be asked to do. Please take time to read the information in this letter and discuss it with others if you wish.

What is the purpose of the research?

The purpose of this research study is to explore the factors contributing to the success of students with albinism studying higher education (HE) in Tanzania and the challenges they have had to overcome. This information is important, as it will inform national and HE policies, particularly in regard to widening participation for the under-represented groups in HE.

Why have you been invited to participate?

You have been chosen purposively because you hold important information on experiences of HE as a student with albinism. This study will involve up to 35 participants, who will be interviewed separately. Each interview will take approximately 60 minutes. I might interview you more than once. If you choose to participate I will organize a location for the interview convenient to you.

Do you have to take part in the study?

Your participation in this research is voluntary. It is up to you to decide whether or not to participate. Your participation will not in any way affect your studies either positively or negatively. If you decide to participate in this research you will be given this information sheet to keep. You will also be asked to sign a consent form. Even after signing the consent form you can change your mind at anytime and withdraw from the study without giving a reason. You can also withdraw you data after you have decided to participate

in the research. However, you will only be able to withdraw your data before the end of August 2013 as after this date I will have begun to analyse the data of this research.

What will happen to you if you take part?

During the session you will be free to stop the interview at anytime if you do not wish it to continue, or if you need a break. The interview will be recorded on audio-recorder and then transcribed onto a computer. The audio-recorder will be stored in a locked secure place at all times and the computer data will also be protected from possible intrusion. The audio-tapes with interviews will be destroyed at the end of the study. Your response will be treated with full confidentiality and only code number or false names will identify anyone who takes part in this research. I am happy to send you a copy of the interview transcript if you wish.

What will happen with the results of this study?

The interviews will be analysed by using computer software operated by myself. At the end of the research I will write a thesis, which will be published. You will not be identifiable in the thesis.

Who has reviewed the study?

This study has been reviewed and approved by the Research Ethics Committee of the University of Sussex, UK.

Contact for further information

You are welcome to contact me by whatever means if you would like any further clarification. My contact details are shown below.

Thanking you for taking your time to read this information.

Yours sincerely

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