

**EXPERIENCES PERCEPTIONS AND UNDERSTANDING OF  
MOTHERS OF CHILDREN LIVING WITH ALBINISM IN MALAWI:  
A QUALITATIVE DESCRIPTIVE STUDY**

**DISSERTATION**

**NAOMI LIKUMBO (LKMNAO001)**

**SUBMITTED TO THE UNIVERSITY OF CAPE TOWN**

**In partial fulfilment of the requirements for the degree**

**MASTER OF SCIENCE IN NURSING**

**FACULTY OF HEALTH SCIENCES**

**DIVISION OF NURSING AND MIDWIFERY**

**DATE OF SUBMISSION: 30 May 2019**

**Supervisor: Emeritus Associate Professor Una Kyriacos (PhD, UCT)**

**Co-supervisor: Dr Tania De Villiers (PhD, UCT)**

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source. The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

The copyright of this thesis vests in the author. No quotation from it or information derived from it is to be published without full acknowledgement of the source.

The thesis is to be used for private study or non-commercial research purposes only.

Published by the University of Cape Town (UCT) in terms of the non-exclusive license granted to UCT by the author.

## DECLARATION

---

I, ...Naomi Likumbo....., hereby declare that the work on which this dissertation/thesis is based is my original work (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other university.

I empower the university to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signature:

Signed by candidate

Date: .....30/5/2019.....

## **DEDICATION**

---

This work is dedicated to my father Mr E. Ndilande and mother, Mrs E. Ndilande, who have so much pride in their children's academic success and my lovely husband Dr. Samuel G. P. Likumbo for sponsoring this study, the encouragement and tireless holistic support throughout my academic journey at the University of Cape Town

To my children, Taona, Methuselah and Praise, thank you so much for your support and prayers.

## **ACKNOWLEDGEMENTS**

---

I am so grateful to Almighty God for giving me the opportunity to conduct this study and give him glory and honour. This project and all the people involved will always be part of my life.

In a special way, I would like to thank my supervisor, Professor Una Kyriacos and my Co-Supervisor, Dr Tania De Villiers for their invaluable support, unending encouragement, guidance and commitment. This study would not have been what it is today without your tireless assistance.

The Queen Elizabeth Central Hospital directors for the hospitality and assistance beyond my imagination, dermatology clinic staff for allowing me to conduct this study in the dermatology clinic and helping me find the informants. Many thanks to you.

To Gerald, Wellington, Enock, Angela and entire family, your support and involvement made things easier for me in Malawi.

Yes, it has been a tough journey but rewarding.

## ABSTRACT

---

**Background:** Albinism affects approximately 1 in 17,000 individuals globally with the highest prevalence in Sub-Saharan Africa with an estimation of 1 in 2000 - 5000 live births and 1 in 2000 live births in Malawi. The total number of people living with albinism in Malawi is estimated to be 7000 - 10,000 of the total population. Albinism is a stigmatised condition particularly in Africa and children are particularly vulnerable.

**Purpose of the study:** to explore and describe the experiences, perceptions and understanding of mothers who have children living with albinism in Malawi.

**Study design:** Qualitative descriptive study.

**Data collection Methods:** The study, conducted between June and July 2018 in Malawi, included voluntary participation of ten mothers 18 years and older who had children with albinism.

Purposive sampling was used to select participants who met the inclusion criteria to answer the research question and achieve the purpose of the study. Semi structured interviews were conducted in the participants' preferred language Chichewa. Interviews were audio recorded and transcribed. Data translation of the questionnaire from English to Chichewa was done by three different translators from Malawi using forward and backward translation. The same process was followed for translation of the data from the interviews.

**Data analysis:** Thematic analysis guided the process of data analysis. Trustworthiness of the data analysis process was maintained. To ensure transparency in reporting the study and to allow replication, reporting guidelines from the equator Network were used to evaluate the quality of the study. The quality of semi-structured interviews was evaluated by using the Consolidated Criteria for Reporting Qualitative Studies (COREQ), a 32-item checklist. The Standards for Reporting Qualitative Research (SRQR) were used to evaluate the quality of the completed study.

**Findings:** Four themes emerged from the data: 1) stigmatisation, discrimination and harm, 2) Mothers' impression of a child with albinism, 3) Mothers' awareness of albinism and 4) Psychosocial effects of albinism.

**Conclusion:** A description of the experiences and perceptions of mothers of children living with albinism in Malawi and their understanding of the condition has revealed that these children are stigmatised and unsafe in their communities and that these mothers experienced this acutely even though they were overwhelmingly positive about accepting and loving their children and attempted to protect them from harm whatever the cost. Being the first such reported Malawian study it has filled a gap in the existing knowledge in this field and provides a foundation for further research specific to people living with albinism in Malawi.

**Key words:** Albinism, albinism in Africa, stigma and albinism, albinism killings in Africa, albinism in Malawi, oculocutaneous albinism.

# Table of Contents

---

---

<b>DECLARATION</b> .....	<b>III</b>
<b>DEDICATION</b> .....	<b>IV</b>
<b>ACKNOWLEDGEMENTS</b> .....	<b>V</b>
<b>ABSTRACT</b> .....	<b>VI</b>
<b>TABLE OF CONTENTS</b> .....	<b>VII</b>
<b>OPERATIONAL DEFINITIONS</b> .....	<b>X</b>
<b>ABBREVIATIONS</b> .....	<b>XI</b>
<b>CHAPTER 1 INTRODUCTION</b> .....	<b>1</b>
1.1 INTRODUCTION.....	1
1.2 BACKGROUND.....	1
1.3 PROBLEM STATEMENT.....	2
1.4 RESEARCH QUESTION.....	2
1.5 RESEARCH AIM AND OBJECTIVES.....	2
1.5.1 <i>Research aim</i> .....	2
1.5.2 <i>Research objectives</i> .....	2
1.6 SIGNIFICANCE OF THE STUDY.....	3
1.7 ASSUMPTIONS.....	3
<b>CHAPTER 2 LITERATURE REVIEW</b> .....	<b>5</b>
2.1 INTRODUCTION.....	5
2.2 SEARCH STRATEGY.....	5
2.3 THE FOLLOWING THEMES WERE IDENTIFIED IN THE PUBLISHED LITERATURE:.....	6
2.3.1 <i>Psychological effects of stigma associated with albinism</i> .....	6
2.3.2 <i>Stigma related to lack of awareness of albinism</i> .....	7
2.3.3 <i>Vulnerability of mothers and children with albinism</i> .....	9
2.3.4 <i>Stigmatisation of children with albinism in societal institutions</i> .....	10
2.4 SUMMARY.....	12
<b>CHAPTER 3 METHODOLOGY</b> .....	<b>13</b>
3.1 RESEARCH DESIGN.....	13
3.2 SETTING.....	13
3.3 STUDY POPULATION.....	13
3.4 SAMPLING AND SAMPLE SIZE.....	14
3.4.1 <i>Selection criteria</i> .....	14
3.4.1.1 Inclusion criteria.....	14
3.4.1.2 Exclusion criteria.....	14
3.5 DATA COLLECTION.....	14
3.5.1 <i>Bracketing</i> .....	14
3.5.2 <i>Data collection tools</i> .....	15
3.5.3 <i>Gaining access to participants</i> .....	15
3.6 DATA COLLECTION PROCESS.....	16
3.7 DATA ANALYSIS.....	17
3.8 RIGOUR.....	19
3.8.1 <i>Trustworthiness</i> .....	19
3.8.1.1 Credibility.....	19
3.8.1.2 Transferability.....	20
3.8.1.3 Dependability.....	20
3.8.1.4 Confirmability.....	20
3.8.1.5 Evaluation of the quality of the study.....	20

3.9	ETHICAL CONSIDERATIONS .....	20
3.9.1	<i>Autonomy</i> .....	21
3.9.2	<i>Non-Maleficence</i> .....	21
3.9.3	<i>Beneficence</i> .....	22
3.9.4	<i>Justice</i> .....	22
3.9.5	<i>Summary</i> .....	22
<b>CHAPTER 4 FINDINGS .....</b>		<b>23</b>
4.1	INTRODUCTION .....	23
4.2	PARTICIPANT CHARACTERISTICS .....	24
4.3	FINDINGS FROM DATA ANALYSIS .....	24
4.3.1	<i>Searching for themes and formulated meanings</i> .....	24
4.3.2	<i>Reviewing themes</i> .....	24
4.3.3	<i>Emergence of themes</i> .....	25
4.3.4	<i>Defining and naming themes</i> .....	25
<b>MAIN THEMES .....</b>		<b>26</b>
<b>MAIN CATEGORIES.....</b>		<b>26</b>
<b>SIGNIFICANT STATEMENTS .....</b>		<b>26</b>
<b>STIGMATISATION, HARM AND DISCRIMINATION .....</b>		<b>26</b>
<b>KILLINGS .....</b>		<b>26</b>
<b>“BEING ACCUSED OF CHEATING WITH ANOTHER MAN”. 7X6, 5X5, 10X5.....</b>		<b>26</b>
<b>MOTHERS’ IMPRESSIONS OF HAVING A CHILD WITH ALBINISM .....</b>		<b>26</b>
<b>ACCEPTANCE.....</b>		<b>26</b>
<b>HEALTH WORKERS’ ATTITUDES .....</b>		<b>26</b>
4.4	MAIN THEME 1: STIGMATISATION, DISCRIMINATION AND HARM .....	26
4.4.1	<i>Sub-theme 1: Killings of people with Albinism</i> .....	26
4.4.2	<i>Sub-theme 2: Labelling of people with albinism</i> .....	27
4.4.3	<i>Sub-theme 3: Rejection by family members, neighbours and husbands</i> .....	29
4.5	MAIN THEME 2: MOTHERS’ IMPRESSIONS OF HAVING A CHILD LIVING WITH ALBINISM .....	30
4.5.1	<i>Sub-theme 1. Acceptance</i> .....	30
4.5.2	<i>Sub theme 2: Mothers perceptions of health workers’ attitudes</i> .....	32
4.6	MAIN THEME 3: MOTHERS’ AWARENESS AND UNDERSTANDING OF ALBINISM .....	33
4.6.1	<i>Sub theme 1: Paucity of information on the real cause of albinism</i> .....	34
4.6.2	<i>Sub theme 2: Lack of clarity on the physiological causes of albinism</i> .....	34
4.6.3	<i>Sub-theme 3: Role of local radio broadcasts</i> .....	35
4.6.4	<i>Sub-theme 4: Awareness of unavailability and expense of sun protective products</i> .....	36
4.6.5	<i>Sub-theme 5: Awareness of poor sight</i> .....	37
4.7	MAIN THEME 4: PSYCHOSOCIAL EFFECTS OF ALBINISM.....	37
4.7.1	<i>Sub-theme 1: Feeling of loss of self-esteem</i> .....	38
4.7.2	<i>Sub-theme 2: Feeling of pain, fear and emotional trauma</i> .....	38
4.7.3	<i>Sub-theme 3: Implications for employment</i> .....	39
4.8	SUMMARY OF FINDINGS.....	39
<b>CHAPTER 5 DISCUSSION, STRENGTHS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION.....</b>		<b>41</b>
5.1	STIGMATISATION, DISCRIMINATION AND HARM.....	41
5.1.1	<i>Killings and labelling of people with albinism</i> .....	41
5.2	MOTHERS’ IMPRESSIONS OF HAVING A CHILD WITH ALBINISM .....	43
5.2.1	<i>Acceptance and rejection by family members and husbands</i> .....	43
5.2.2	<i>Health workers’ attitudes</i> .....	44
5.3	MOTHERS’ AWARENESS AND UNDERSTANDING OF ALBINISM.....	44
5.3.1	<i>Paucity of information on the cause of albinism</i> .....	45
5.3.2	<i>The role of local radio broadcasts</i> .....	46
5.3.3	<i>Awareness of unavailability and expense of sun protection products</i> .....	46
5.3.4	<i>Awareness of poor eyesight</i> .....	47
5.4	PSYCHOSOCIAL EFFECTS OF ALBINISM .....	47

5.4.1	<i>Feeling of loss of self-esteem</i> .....	47
5.4.2	<i>Pain, anger, shame and emotional trauma</i> .....	47
5.4.3	<i>Implications for employment</i> .....	48
5.5	STRENGTHS OF THE STUDY .....	48
5.6	LIMITATIONS OF THE STUDY .....	49
5.7	RECOMMENDATIONS .....	49
5.7.1	<i>Recommendations for health science educational institutions</i> .....	49
5.7.2	<i>Recommendations for other education institutions</i> .....	50
5.7.3	<i>Recommendations for health care clinical areas</i> .....	50
5.7.4	<i>Recommendations for Policy Makers in the Ministry of Health at regional level in Malawi</i> ....	51
5.7.5	<i>Recommendations for society</i> .....	52
5.7.6	<i>Recommendations for Social Media platforms</i> .....	52
5.7.7	<i>Recommendations for further research</i> .....	52
5.8	CONCLUSION.....	53
<b>REFERENCES</b> .....		<b>54</b>
<b>APPENDIX 1</b> .....		<b>57</b>
<b>APPENDIX 2: INFORMATION SHEET</b> .....		<b>59</b>
<b>APPENDIX: 3</b>	<b>CONSENT FORM (FLESCH KINCAID 9.5)</b> .....	<b>62</b>
<b>APPENDIX 4: INTERVIEW GUIDE</b> .....		<b>63</b>
<b>APPENDIX 5</b>	<b>ETHICS APPROVAL LETTER FROM (UCT)</b> .....	<b>65</b>
<b>APPENDIX 6</b>	<b>PERMISSION LETTER FROM (QUECH)</b> .....	<b>66</b>
<b>APPENDIX 7</b>	<b>ETHICS APPROVAL LETTER FROM (NCSRH)</b> .....	<b>67</b>
<b>APPENDIX 8: TRANSCRIPTIONS BY QUESTION</b> .....		<b>69</b>
<b>APPENDIX 9</b>	<b>INDIVIDUAL PARTICIPANTS' TRANSCRIPTS</b> .....	<b>75</b>
<b>APPENDIX 10: CODED DATA</b> .....		<b>88</b>
<b>APPENDIX 11: SEARCHING FOR THEMES</b> .....		<b>94</b>
<b>APPENDIX 12: REVIEWING THEMES, CATEGORISING THEMES AND CLUSTER THEMES</b> .....		<b>102</b>
<b>APPENDIX 13: DEFINING AND NAMING THEMES</b> .....		<b>107</b>
<b>APPENDIX 14: CONSOLIDATED CRITERIA FOR REPORTING QUALITATIVE STUDIES (COREQ)</b> .....		<b>110</b>
<b>APPENDIX 15: STANDARDS FOR REPORTING QUALITATIVE RESEARCH (SRQR)</b> .....		<b>113</b>

## **Operational definitions**

---

Albinism - a condition that results from failure of the body to produce melanin (Kimbassa, 2016:1).

Genetics - study of how characteristics of living things are transmitted from one living thing to another (Kimbassa, 2016).

Napweri refers to dry pigeon peas.

Mzungu means a white person in East Africa ((Serrano de la Vega, 2015).

Mwenye means an Indian in Malawian language.

Mwanamphepo. An ancestral skin condition which is believed to cause disease in new born children if the mother has the condition when giving birth (Braathen & Ingstad, 2006).

## **Abbreviations**

---

- HREC: Human Research Ethics Committee (University of Cape Town guideline)
- QUECH: Queen Elizabeth Central Hospital
- MBC: Malawi Broadcasting Cooperation
- NCRSH: National Committee on Research in the Social Sciences and Humanities (Malawi)

# CHAPTER 1 INTRODUCTION

---

## 1.1 Introduction

This dissertation is a qualitative study aimed at exploring the experiences, perceptions and understanding of albinism of mothers of children living with albinism in Malawi because there is a dearth of published literature on this aspect of albinism and specifically from a Malawian perspective. In 2006 Braathen and Ingstad reported that at the time there was no current or previously available scientific literature on albinism in Malawi. A subsequent systematic review on Oculocutaneous Albinism in Sub-Saharan Africa excluded Malawi (Wright et al., 2012) and did not address the focus of the present study. However, the limited studies that have been conducted indicate a strong link between albinism and medical problems such as poor vision (Tandon, 2016) and dermatological problems, such as skin spots to all exposed parts of the body, thus putting an individual at risk of developing skin cancer (Kimbassa, 2016). People with albinism have also been stigmatized as being disabled (Braathen & Ingstad, 2006). The psycho-social effects of stigmatization are a major problem as children with albinism are considered bad luck and are often abused or killed as a result (Braathen & Ingstad, 2006). There are studies on the prevalence of albinism in Malawi but not related to the topic under study.

Malawi is one of the developing countries located in South East Africa with a population of 17,563,749 (Government of Malawi National Statistical Office, 2018:8). Albinism affects approximately 1 in 17,000 individuals globally with the highest prevalence in Sub-Saharan Africa with an estimation of 1 in 2000-5000 live births and 1 in every 2000 live births in Malawi (Seibert & Darling, 2013). The total number of people living with albinism in Malawi is estimated to be 7000- 10,000 of the total population (Amnesty International News, 2016:3). The present study was conducted to better understand the experiences, perceptions and understanding of albinism of mothers of children living with the condition, and thus to contribute to the current body of knowledge on this phenomenon in Malawi. Such knowledge is essential for the provision of quality nursing care for the population of persons living with albinism and their families. Melanin is a natural pigment found in an individual's skin, hair and eyes. Melanin protects the skin from ultra-violent light and determines an individual's skin colour. Albinism is caused by failure of the human body to produce melanin or sufficient quantities (Kimbassa, 2016).

## 1.2 Background

Albinism makes an individual look different in a black community and persons with this condition are sometimes referred to as white skinned people (Kimbassa, 2016). Albinism is a stigmatised condition particularly in Africa. A study conducted in Malawi defines a stigmatised person as

someone who possesses undesirable characteristics that are not within the normal characteristics in the category to which he belongs (Braathen & Ingstad, 2006). Children living with albinism are stigmatised from birth and therefore are a vulnerable population. The focus of this study was to explore and describe the experiences, perceptions and understanding of albinism of mothers of children living with albinism in Malawi.

### **1.3 Problem statement**

Mothers of children living with albinism in Malawi have expressed concern about receiving inadequate information on albinism (Braathen & Ingstad, 2006). In interviews with some of these mothers, Braathen and Ingstad (2006) found that the mothers wanted to learn more about the cause of albinism to use the information to educate their community about keeping their children safe (Braathen & Ingstad, 2006). Mothers also expressed concern that women and children were easily targeted because of their vulnerability (Flanagan & Newton, 2016). The few available studies that had been conducted in Malawi concentrated on the disability, vision problems and stigma associated with albinism, and not on the experiences, perceptions and understanding of mothers raising children with albinism (Thwala, Ntinda, & Hlanze, 2015). This topic was chosen for investigation to fill the knowledge gap that has been identified in the published literature and because the researcher is a registered nurse, midwife and child nurse specialist who deals with children from birth to 18 years of age with different genetic conditions including albinism.

### **1.4 Research question**

What are the experiences and perceptions and understanding of mothers of children living with albinism in Malawi and what is their understanding of the condition?

### **1.5 Research aim and objectives**

#### **1.5.1 Research aim**

The aim of the study was to explore and describe mothers' experiences, perceptions and understanding of mothers who have children living with albinism in Malawi.

#### **1.5.2 Research objectives**

The study objectives were:

1.5.2.1 To describe the experiences and perceptions of mothers of children living with albinism in Malawi.

1.5.2.2 To describe research participants' understanding of albinism.

## **1.6 Significance of the study**

Findings of this study may inform child nursing and midwifery practice for more effective nursing interventions when dealing with mothers of children who have albinism. Effective nursing and midwifery interventions should include “reflection on practice” (reflection-on-action) that is, thinking back on what we have done to discover how our knowledge may have contributed to an unexpected outcome (Schon, 1983:26) and “reflection in practice” (reflection-in-action) that is, reflecting on an incident while it can still benefit that situation rather than reflecting on how one would do things differently in the future (Schon, 1983:68). In addition, effective interventions include good communication skills and knowledge translation to empower mothers of children who have albinism with knowledge and understanding to cope with such a situation. At a broader level, the findings might create awareness amongst other health practitioners and the local community about the facts relating to albinism and result in a safer society.

## **1.7 Assumptions**

Assumptions are basic guidelines for a research problem; without assumptions no research can exist (Simon & Goes, 2013). It is important to declare biases, assumptions and predispositions to separate what is already known from the participants’ views (Shosha, 2012).

A qualitative descriptive study was the method of choice because “straight descriptions of phenomena were desired” (Sandeloweski, 2000:334) and appropriate for true descriptions of participants’ perceptions of albinism without interpreting or predicting their ideas.

The researcher holds the following assumptions about the experiences of mothers of children living with albinism:

- The researcher has never raised a child with albinism and was interested to know about the experiences of mothers who have children living with albinism.
- The researcher’s assumption was limited by having no scientific evidence regarding the experience and not having first-hand information from mothers of children with albinism.

### **Presuppositions held:**

- It is assumed that mothers of children living with albinism feel segregated and live in fear due to the white appearance of their children in a black community and that they lack understanding of the cause of albinism and knowledge about albinism in general.
- Mothers might perceive their children to be disabled and themselves and their children as being vulnerable due to the albinism.

Chan, Fung, and Chien (2013) indicate that researchers should not impose their ideas, knowledge and beliefs and that during the data collection process; they should describe only the participants’

life experiences. These assumptions helped the researcher to identify relevant literature which supports the experiences of mothers of children living with albinism and to value the views of the participants.

The assumptions also helped the researcher to be open to participants' views on their lived experience, perceptions of raising children with albinism and their understanding of albinism as a basis for the knowledge produced by this study particularly as there is not much existing literature. The next section is an overview of the literature reviewed for this study.

## CHAPTER 2 LITERATURE REVIEW

---

### 2.1 Introduction

This section will cover important published literature on albinism from Africa and particularly from Malawi. The literature review guided the formulation of an interview schedule for this study and also helped the researcher to better understand the research question and to defend the proposal to the gatekeepers (Chan et al., 2013).

A literature search was undertaken limited to English publications, peer-reviewed journal articles excluding animal research published between 2000 and 2017, exceeding the usual 10-year period. Search engines such as PubMed, Medline via EBSCOhost and CINAHL via EBSCOhost were used for MeSH keywords albinism\* AND albinism in Africa, yielding 298,191 and 4 references respectively. Only four references were relevant, the rest were about genetic types of albinism and oculocutaneous and other medical complications. References in published papers were hand searched to augment the search strategy.

### 2.2 Search strategy

Results from the literature search from the databases are presented in Table 2-1. No published literature about the experiences of mothers of children with albinism in Malawi was found, but articles which contained information that could answer some aspects of the research question and met the study objectives were included in the references.

**Table 2-1: Literature search strategy and results**

Database/Search Engine	Keywords and Phrases	Number of relevant papers	Number used
EBSCOhost CINAHL	Albinism* AND albinism in Africa, Albinism in Africa, stigma and albinism, albinism killings in Africa Albinism in Malawi, albinism and stigma, oculocutaneous albinism	4	4
EBSCOhost Medline		28	5
Africa-Wide Information		55	5
PubMed		177	11
PsycINFO		12	2
Academic premier		23	5
Google Scholar		7,870	10
Total		8,169	42

## **2.3 The following themes were identified in the published literature:**

- Psychological effects of stigma associated with albinism
- Stigma related to lack of awareness of albinism and advocacy
- Vulnerability of children and women with albinism
- Stigmatisation of children with albinism in societal institutions

Each theme and the psychological and physiological sequelae of the stigma associated with albinism, which are almost inseparable, are discussed below.

### **2.3.1 Psychological effects of stigma associated with albinism**

Albinism is defined and described in various ways. For example, a study conducted in Tanzania (Masanjala, 2014) described albinism as a curse due to past misdeeds within the family. Cruz-Inigo, Ladizinski, and Sethi (2011) described albinism as a genetic disorder resulting in a decrease or absence of pigmentation in the hair, eyes and skin which make people look different. Albinism has also been described as a worldwide public health problem but on the African continent albinism is considered a strange phenomenon linked to the social stigma faced by people with albinism (Imafidon, 2017). Some authors have reported that albinism is a group of related conditions which are a result of alterations in the hereditary material of life, leading to a deficiency in the production of melanin which affects the appearance of an individual (Brocco, 2015).

Stigma is defined as a recognition of the differences and devaluation which is associated with social rejection, avoidance, dehumanization, discrediting and depersonalisation of other people. The stigma that people with albinism face is at an individual, family and societal level. Perceptions of stigma have a psychological impact on those associated with a stigmatised person (Bos, Pryor, Reeder, & Stutterheim, 2013).

Fayoyin and Ihebuzor (2014) conducted a case study using secondary data including national reports, project documents, media analyses and government statements. Findings indicated that people with albinism encounter psychological and medical challenges. Furthermore, people with albinism are hunted down by hirelings of witchcraft practitioners who believe that their body parts are a source of wealth. Living with albinism results in fear to the point of failing to do any business or farming. Fayoyin and Ihebuzor recommended that advocacy was fundamental to changing society's attitude. Due to the stigma and the associated superstitions about albinism, even children have been attacked and killed and their body parts used for witchcraft purposes (Cruz-Inigo, Radzinski & Seth, 2011).

Hong, Zeeb, and Repacholi (2006) reported similar results in a study which involved a systematic electronic search of articles in PubMed. One of the findings was that people with albinism endure segregation from society and sometimes they isolate themselves for fear of being abused. The authors recommended public awareness as one of the measures to address physical and psychological issues

encountered by people with albinism which can be achieved by including albinism in school curricula where pupils are oriented to the causes of albinism. The report also stated that counsellors undergoing training and health workers in clinics and hospitals need to be educated on the medical and psychological problems associated with albinism and measures which can be put in place to address these problems.

A qualitative phenomenological study was conducted to examine the life experiences of people with oculocutaneous albinism in South Africa (Pooe-Monyemore, Mavundla, & Christianson, 2012), and most respondents appreciated the work done by the Department of Health for promoting awareness through genetic counselling. Respondents suggested that emphasis should be placed on the cause of albinism as it was perceived by some respondents that information on the condition was insufficient. Some of the themes that emerged from the study indicated that the Department of Education should ensure that teachers are knowledgeable about the condition to be able to support and promote self-esteem, development and growth in learners with albinism (Pooe-Monyemore et al., 2012).

Similar to the report by Cruz-Inigo et al., (2011) the findings of a study conducted in South Africa to explore beliefs and practices regarding albinism (Phatoli, Bila, & Ross, 2015), confirmed the existence of myths, stigma and social problems encountered by people with albinism. The report stated that many people with albinism do not fit well either in an African community or in a white community, because despite being white in colour, they also possess features of a black person, and they are discriminated against (Phatoli, Bila & Ross 2015). A study conducted in Malawi between 2010 and 2011 indicated that the very visible difference in appearance of those living with albinism can lead to lack of acceptance and a poor social life (Lynch, Lund, & Massah, 2014).

Reports have indicated that people with albinism are segregated in various ways by being labelled as “others” due to societal beliefs that are used as a justification to protect themselves from death, curses, suffering and many evil things which are believed to be associated with albinism (Imafidon, 2017).

### **2.3.2 Stigma related to lack of awareness of albinism**

A study conducted in Tanzania in 2014 to assess level of awareness of people with albinism and the level of predicament faced by members of their households, revealed that people with albinism are considered disabled and marginalised (Masanjala, 2014). In this study, stigma was found to be associated with low levels of education since most negative attitudes came from people who lacked knowledge of albinism. It was also found that many women were divorced by their husbands and accused of sleeping with men from other races, accused of being unclean or cursed due to a knowledge deficit regarding albinism (Masanjala, 2014). Segregation occurs in communities steeped in traditional myths and beliefs because they lack knowledge of the genetic cause of albinism.

Similarly, Cruz-Inigo et al. (2011) found that poverty and illiteracy in many parts of Africa may result in lack of awareness of the causes of albinism which contributes to stigma. The report stated that one of the misconceptions regarding albinism is that a pregnant woman must have slept with a white man or, the devil must have replaced the normal child with the one with albinism, and this also leads to stigma. The authors recommended awareness campaigns to help society to understand the cause of albinism.

Baker, Lund, Nyathi, and Taylor (2010) also reported that stigmatisation is associated with a knowledge deficit, because despite conducting studies and reporting on the genetic cause of albinism in Africa, researchers have not communicated enough of their study results to society, and this has led to misunderstandings of the condition and the formation of a stigma cycle. To promote awareness, more research must be done and funding is needed for organising seminars and workshops related to albinism (Imafidon, 2017). The author indicated that health workers stand a greater chance of educating society about albinism as they are involved in the care of people with albinism at all stages of life. He also recommended counselling centres to be established in all health settings to educate mothers of children with albinism about the cause of albinism and care of persons with the condition (Imafidon, 2017).

Franklin, Lund, Bradbury-Jones, and Taylor (2018) reported that people with albinism in Africa face barriers that prevent them from being accepted in their community as a human being, and this leads to infringement of their right to a fulfilling life at a personal level and a right to education. If children do not get an education, discrimination continues into adult life because they end up having challenges finding proper jobs. Kisanga and Mbonile (2017) reported that killing people with albinism is an infringement of their right to life.

Kisanga and Mbonile (2017) conducted a study in two districts of the Shinyanga region in the southern zone of Lake Victoria in Tanzania to explore the effects of interventions put in place following the murder and mutilation of people with albinism. No positive effects were reported. One of the findings that more people attended school only up to primary level and few proceeded with tertiary level studies may have contributed to the formation of the cycle of traditional beliefs against people with albinism and discrimination. Recommendations were made for the government to collaborate with other stakeholders to assess and coordinate interventions in areas where people with albinism are being killed.

Allawh and Norton (2014) reported on one of Tanzania's advocates for people with albinism "Josephat Tomer" who shared his dream of looking forward to seeing people with albinism being respected as human beings. The report indicated that since the year 2000, stigma resulted in 200 people with albinism in East Africa having been killed or body parts amputated. Josephat made a plea to local and international organisations to assist in protecting the rights of people with albinism.

### **2.3.3 Vulnerability of mothers and children with albinism**

The literature shows that children are more stigmatised than adults due to their vulnerability. Lynch et al. (2014) reported that children with albinism are faced with cultural and social situations which affect them negatively due to their vulnerability. Mswela (2017) reported that children with albinism experience a lot of violence including killings in South Africa because of their vulnerability, and this leads to violation of the child's right to life and optimal development stated under article 6 of the Convention of Children' rights. Findings of a study conducted in Zimbabwe in 2013, showed that girls and women with albinism are victims of rape and violence because men with HIV/AIDS believe that they can be cured of the disease. The report also indicated that babies were also killed by being exposed to a harsh climate and environmental conditions by suffocation or sometimes by burying them alive (Machoko, 2013).

Many children with albinism are raised by their mothers because their fathers abandon them immediately after birth and this leads to poverty and segregation of these single mothers (Baker et al., 2010). Similarly, Cruz-Inigo et al. (2011) reported stories of children with albinism being killed, kidnapped and body parts amputated which may contribute to psychosocial distress to mothers of children with albinism. Machoko (2013) stated that correct information about the causes of albinism need to be communicated clearly to the society in Africa to end the abuse inflicted on people with albinism.

In support of reports by Cruz-Inigo et al (2011) and Baker et al (2010), Bos et al. (2013) pointed out that stigma does not only affect individuals who possess a stigmatised condition but also those related to them. Such people also experience low social esteem and become psychologically affected, and some try to hide their relationship to a stigmatised family member, and this could be one of the reasons why fathers do not want to be recognised as the fathers of children with albinism and they then abandon their own children. Similarly, Franklin et al. (2018) reported that stigmatisation starts in childhood where children are abandoned by their own family and this creates financial problems which affect the children's education and access to health care services. While there were some stories of both parents loving their children these were in the minority compared to those who rejected their own children (Bradbury-Jones, Ogik, Betts, Taylor, & Lund, 2018).

In Tanzania a case study of a 28-year-old woman living with albinism combined with episodes from the lives of other informants living with albinism were analysed to understand the social relationships between individuals with albinism and other social relationships. It was found that many people with albinism in Tanzania live in marginalised social conditions and they face economic challenges because they cannot participate in many outdoor activities due to their skin sensitivity to sunlight (Brocco, 2015).

### **2.3.4 Stigmatisation of children with albinism in societal institutions**

In a report drawn from a number of research studies, psychologists stated that a social environment has an important role to play in either prolonging or eradicating stigma and that stigma is harmful because it lowers an individual's self-esteem and may cause psychological problems which may affect academic progress, professional achievement and mental health (Watson, 2012). Brocco (2015) reported that people with albinism experience stigma in many different ways in schools.

In a qualitative participatory study conducted in Malawi over a two-year period in which interviews were conducted with children with their parents and primary school teachers, Lynch et al. (2014) indicated that albinism is associated with eye problems such as poor vision, photophobia and uncontrollable movement of eyes. The authors reported that if these problems are not managed, they affect the social lives of people with albinism. Some parents of children with albinism in the study expressed concern that many children in mainstream education learn without visual support and this affects their academic progress. The report indicated that many parents expressed dissatisfaction with the level of care and protection received by their children from some classroom teachers especially during outdoor activities such as sports. Some parents reported that they preferred sending their children to residential resource teaching centres where their children are not stigmatised and their needs are accommodated.

In a systematic review, Tandon (2016) described a person with albinism as being as healthy as any other person considering that albinism itself does not cause mortality. However, albinism is associated with eye problems some of which some can be corrected with glasses and other visual aids such as hand-held devices, large printed materials, magnifiers or coloured contact lenses. Franklin et al. (2018) reported that children with albinism have the right to education and attention must be given to ensure that they have support such as visual aids in mainstream educational settings. Sometimes this can be achieved by minor alterations in classrooms such as using visual aids and a change of attitude amongst teachers and pupils because some teachers and students respectively, do not like to use low visual aids devices despite their availability, and this works to the disadvantage of the affected pupils.

An interpretive qualitative study was conducted at the University of Venda in South Africa which recruited ten students with albinism to explore their beliefs and practices and the availability of resources. It was found that many students with albinism can participate in mainstream schools as long as appropriate measures such as wearing glasses are taken to help them cope with their low vision (Phatoli et al., 2015).

A study which included 120 pupils was conducted in Malawi in 2015 (Schwering et al., 2015) using both qualitative and quantitative methods in government primary schools. The study focused on

describing refractive errors and whether pupils with albinism in Malawi benefit from correction of refractive errors. It was found that many learners with poor sight were more disadvantaged than their peers but that correction of refractive errors improved their visual acuity (Schwering et al., 2015).

Bradbury-Jones et al. (2018) indicated that albinism adversely affects vision causing photophobia, squint and rapid involuntary movement of the eyes resulting in poor vision and most children cannot afford health services due to financial challenges. The authors reported that school teachers can be of great importance in challenging stereotypes and advocating for these children.

An ethnographic study was conducted in central Tanzania between 2012-2014 which employed both structured and semi-structured interviews as well as focus group discussions with people with albinism, their relatives, non-governmental Organisations (NGOs) and religious leaders. Findings of the study indicated that many children with albinism experienced eye problems such as photophobia, uncontrollable movement of eyes and poor sight. The report stated that although some of these problems are controllable, many people with albinism live in poverty due to unfair distribution of political power and economy therefore they cannot afford ophthalmic services such as glasses or sunglasses and their academic progress is slow (Brocco, 2015).

In support of Brocco's 2015 study findings, the literature shows that almost all children with albinism have some kind of visual impairment problem which hinders activities such reading and seeing on a blackboard which are necessary for learning. Many learners cannot afford proper visual aids due to poverty or lack of access to health care and this affects their education and the poverty cycle and stigma prevails (Cruz-Inigo et al., 2011).

In addition to poor eye sight, Rudan, Boschi-Pinto, Biloglav, Mulholland, and Campbell (2008) reported that children with albinism also have skin rashes which requires them not to be exposed to too much sun if not wearing protective clothing. Skin diseases at times develop into cancer and these problems predispose them to societal stigma. Phatoli et al. (2015) stated that people with albinism are particularly vulnerable to skin cancer due to a shortage or absence of melanin and they could benefit from protective sun creams. In tropical countries these skin problems may develop into skin cancers if no protective sun cream is used due to lack of accessibility to health care (Braathen & Ingstad, 2006). Public measures should be put in place to minimise problems that result from the harmful effects of the sun but even if in place, these measures do not succeed due to lack of resources but even with the availability of the resources, people with albinism delay seeking medical attention because of the stigma experienced from their community members and they attend the skin clinic when the skin lesions have advanced into cancer (Lekalakala et al., 2015).

Many families in Africa do not have enough funds to send their children to school, and as a result of having no education, employment becomes a challenge and they end up cultivating their own farms or being hired by other farmers but this type of work exposes their sensitive skin to sunlight. This

puts them at risk of developing skin cancer (Brocco, 2015). Many people with albinism are sensitive to the effects of the sun and harsh sunlight causes skin cancer which contributes to discrimination in terms of employment. Employers perceive them as unproductive since they cannot work if exposed to the harmful effects of the sun without sun protection products and clothing.

## **2.4 Summary**

In the available literature no reference was made to the experiences and perceptions of mothers of children with albinism or their understanding of albinism. Research designs conducted to explore stigma associated with people living with albinism included mostly qualitative studies and only a few employed quantitative and mixed methods. The intention of this study is to fill a gap in the literature.

The published literature on stigma associated with albinism is from African countries including Malawi. Factors that contribute to stigma include differences in appearance and lack of awareness of the cause of albinism. Stigma is present within society and also in school and university settings. Stigma is associated with barriers to education and improvised measures to substitute low vision aids are used in the absence of recommended visual aids to accommodate pupils with albinism who have eye problems due to economic constraints.

The psychological and physiological sequelae of the stigma associated with albinism are almost inseparable and tragic, resulting in abandonment, social rejection, social isolation, feelings of being dehumanized, discredited, depersonalised, disempowered, fear of abuse, maiming and being murdered, false accusations of marital infidelity, poverty, neglect and infringement of human rights.

In the next chapter the methodology employed in the present study is described.

## **CHAPTER 3    METHODOLOGY**

---

This chapter describes all the steps that were followed in conducting this study. It includes a description of the research setting, study population, sampling, procedures and tools for data collection and analysis, rigour and trustworthiness and how these were achieved and ends with ethical considerations. Declaration of Helsinki that guided the study (WMA, 2013).

### **3.1    Research design**

“A qualitative descriptive study was the method of choice because straight descriptions of phenomena were desired” (Sandelowski, 2000:334). A descriptive qualitative research design was used for this study to differentiate it from other kinds of qualitative designs such as phenomenology, grounded theory and ethnography. “Researchers conducting qualitative descriptive studies stay close to their data and to the surface of words and events” (Sandelowski 2000:334). Qualitative descriptive designs generally are selective but suitable combination of sampling, and data collection, analysis, and re-presentation techniques. Although the design is less interpretive than other forms of qualitative designs such as phenomenology, it is more interpretive than quantitative description because it does not employ a structured survey and it will not generate descriptive statistics (Sandelowski, 2000). Qualitative descriptive design draws on the tenets of naturalistic inquiry in its commitment to studying something as it is (Creswell & Miller, 2000). This design was appropriate for a true description of participants’ perceptions of albinism from their reality: Mothers described their lived experiences in raising their children living with albinism.

### **3.2    Setting**

Participants were interviewed in the setting where people living with Albinism receive follow up treatment for skin disorders, that is, at the doctor-led Queen Elizabeth Central Hospital (QUECH) dermatology clinic in Malawi. The QUECH is one of the government central hospitals located in the Blantyre district in the southern Region of Malawi which also acts as a referral hospital for all districts surrounding Blantyre and is located along the Chipembere Highway, the main transport route which makes it easily accessible.

### **3.3    Study population**

The study population consisted of mothers of children living with albinism who attended the dermatology outpatient clinic at the QUECH in Blantyre, Malawi.

## **3.4 Sampling and Sample size**

Purposive sampling was used to select participants who met the selection criteria to answer the research question and to achieve the purpose of the study (Denzin & Lincoln, 2000). Purposive sampling is subjective as the researcher selects participants who have experience of the phenomenon under investigation to gain rich information. In this study the researcher had no prior relationship with the participants who were selected according to the selection criteria described in Section 3.4.1.

There is no fixed sample size in qualitative research but the number of participants is determined when data saturation is reached, i.e. when new participants do not provide additional information. Malterud, Siersma and Guassora (2016: 1758) prefer the concept ‘information power’ to “saturation” to guide determination of an adequate sample size for qualitative interview studies. Information power indicates that the more information the sample holds, relevant to the actual study, the lower the number of participants that is needed. A sample of 10 participants were adequate because data saturation was reached.

### **3.4.1 Selection criteria**

#### ***3.4.1.1 Inclusion criteria***

- Mothers aged 18 years and older of children aged 0 to 18 years of age who have albinism. The age of the mothers was guided by the Convention on the Rights of a child, which states that every individual under the age of 18 is considered a child (United Nations Convention on the Rights of the Child, 2015).
- Mothers who could speak either English or Chichewa fluently, because these are the official languages in Malawi.
- Mothers of children with albinism who attend the QUECH dermatology clinic.

#### ***3.4.1.2 Exclusion criteria***

- Unmarried mothers under 18 years of age who have children with albinism and attend the dermatology clinic because they are considered a vulnerable group in Malawi where marriage is only allowed from 18 years of age.

## **3.5 Data collection**

### **3.5.1 Bracketing**

Bracketing refers to the process where the researcher attempts to be, as far as is humanly possible, free of bias (Lincoln and Guba, 1986). For purposes of this study, the researcher wrote down everything she knew and believed about albinism prior to commencement of data collection. The

researcher set the notes aside to enable her to adopt a more neutral position while conducting the study (Creswell, Hanson, Clark Plano & Morales, 2007) . Bracketing was necessary since the researcher is a Malawian resident and familiar with the socio-emotional challenges that face families who have children living with albinism.

### **3.5.2 Data collection tools**

An interview guide with 18 open-ended questions was designed in English (Appendix 4) for conducting individual semi-structured interviews. The interview guide was translated into Chichewa using forward and backward translation as cited by (Tsang, Royse, & Terkawi, 2017). For forward translation, an English and Chichewa speaking nursing school health professional unrelated to the study but familiar with the terminology of the contents of the instrument, provided a translation of the original instrument to Chichewa. The second translator, a primary school teacher fluent in English and Chichewa who was also unaware of the objective of the questionnaire, produced the second translation from English to Chichewa so that subtle differences in the original questionnaire could be detected. Discrepancies between the two translators were discussed and resolved between the nursing school health professional and the primary school teacher.

Backward translation, that is, a translation from the target language (Chichewa) into the original language (English) was undertaken by a nurse unrelated to the study (Tsang et al., 2017) but familiar with the terminology of the study field covered in the instrument. The primary school teacher who did the forward translation also did the backward translation to ensure the accuracy of the translation which is not ideal but the other identified primary school teacher had unexpectedly lost a brother in a car accident and was emotionally traumatised. Due to time constraints it was difficult to find a replacement translator. Both translators compared notes and made the necessary changes that is, words which were not clearly understood and long sentences were simplified until both translators were satisfied.

### **3.5.3 Gaining access to participants**

The process of recruitment and data collection started after ethics approval by the Human Research Ethics Committee (HREC) of the Faculty of Health Sciences of the University of Cape Town (Appendix 5) and the National Committee on Research in the Social Sciences and Humanities in Malawi (Appendix 7). The researcher sent a letter (Appendix 1) to the hospital Director and a copy to the Chief Nursing Officer at the QUECH in Blantyre requesting permission to conduct the study in the dermatology clinic which is attended by people with albinism for skin assessment and a supply of sun protection cream. The researcher was informed that before implementation of the study, the proposal had to be reviewed again and approved by the ethics committee in Malawi. Thereafter, the hospital director issued a letter of permission (Appendix 6) to the researcher which was sent together

with the proposal to the National Committee on Research in the Social Sciences and Humanities (NCRSH) in Malawi for review and statistical purposes. After the reviewing process, the researcher was provided with an approval letter from the NCRSH (Appendix 7).

The doctor in charge of the dermatology department had been informed about the study by the deputy hospital director. Nevertheless, the researcher took along the HREC approval letter (Appendix 5) and the two local letters (Appendix 6 and 7) respectively, list of Inclusion and Exclusion criteria for participants, information sheet and consent form to the clinic to explain details of the study. The researcher requested the doctor to assist in identifying potential participants. After explaining the study to each potential participant, the researcher gave each person an information sheet and consent form and read it through with them to ensure they completely understood what their participation would entail and to deal with any questions. Participants were informed that they could take the consent form home to discuss it with their families and then return the form at their next appointment or communicate a day that was convenient for them. Those who wished to sign their consent form immediately after the explanation did so.

### **3.6 Data collection process**

The main method of data collection was semi-structured interviews. According Gill et al. (2008:291) “semi-structured interviews allow for the discovery or elaboration of information which is important to participants but may not have previously been thought of as pertinent by the research team”. Several key questions (Appendix 4) helped to define the areas which needed to be explored during the semi-structured interviews and allowed the interviewer or interviewee to diverge to pursue an idea or response in more detail. Interviews were conducted in a quiet environment and privacy was maintained to allow participants to speak comfortably. Prior to commencement of the individual interviews, the researcher explained the topic of the study and responded to all questions to create a rapport with the participants. Participants were asked whether they would prefer to be interviewed in Chichewa or English but all participants, even those who could speak English preferred to be interviewed in Chichewa (their home language). Participants were told that a spare room was set aside for their children in case they could not be comfortable to be interviewed in the presence of their children.

Participants were requested to choose pseudonyms for the audio recording. All participants were asked the same questions and each question had a follow-up question to gain rich information regarding their experiences, perceptions and understanding as mothers of children living with albinism. Interviews were recorded on my mobile phone (Edward & Welch, 2011) using a default voice recording app. During the interviews, the researcher was flexible, allowing mothers to speak without interruption while writing down important points (Creswell, 2009) and observing non-verbal signs of emotion such as sadness, tears, facial expression and posture. The researcher had previously

completed two courses in the principles of genetics counselling at Masters' level so she was able to interpret non-verbal signs. The researcher iteratively reflected on responses and probed throughout the interview to gain rich information from participants. Cold drinks were provided to ensure that participants were comfortable. It took 30-45 minutes to complete each interview. At the end of each interview, arrangements were made on how to contact participants again for confirmation of the research findings, and all participants preferred to be contacted telephonically. Each participant was interviewed once during the three weeks of data collection.

The researcher conducted four semi-structured interviews with four participants on 28 June, four on 5 July and the last interview with two participants on 12 July, 2018. There was no set sample size at the start of the study but the decision was determined when data saturation was reached, that is, when new participants could not provide additional information (Malterud, Siersma, & Guassora, 2016). Transcriptions (that were all in Chichewa), were back translated into English (Tsang, Royse and Terkawi, 2017) by a previously identified nurse and a primary school teacher as described in Section 3.5.2.

### **3.7 Data analysis**

“Data analysis involved preparation and coordinating data, reducing the data into themes and interpreting results” (Lewis, 2015:142) Data analysis for this study was done manually through thematic analysis. Thematic analysis is commonly used in qualitative research (Clarke & Braun, 2013) and is a method of coding and analysing data systematically. This made it a suitable method of data analysis for this study. The following steps were followed for thematic data analysis: familiarisation with the data, coding, searching for themes, reviewing themes, defining and naming themes and writing up (Clarke & Braun, 2013).

#### **1. Familiarisation with the data**

The researcher listened to digitally recorded data a number of times then data were transcribed (Appendix 9). Each transcript was read and re-read to obtain a general sense of the content and to become familiar with the content as described by the participants (Shosha, 2012). After familiarisation with data, the next step was coding.

#### **2. Coding**

Coding is the process of categorizing data and describing the details of these categories (Trochim, 2006). For each transcript, significant statements that related to the mothers' experiences, perceptions and understanding of children living with albinism in Malawi were extracted by coding (Appendix 10) and were colour-coded, recorded on a separate sheet and labelled according to their pages and code line numbers (Edward & Welch, 2011). An example of significant statements that

were identified from transcriptions for each question for each participant and coded are shown in Table 3.1.

**Table 3.1: Example of coding of significant statements**

Significant statements	Transcript number	Page number	Lines number code
After my child was born the nurse told me that it was born with albinism and I accepted it without problems.	1	1	1X1
I think they did not want to disappoint me or, they were also interested with how the child was looking”.	3	5	3X4

After coding, the next step was to search for themes:

### 3. Searching for themes

Ruggunan (2012) defines this step of analysis as an active process and encourages researchers to use the active voice. The researcher examined the codes and collated data to identify significant common themes (Shosha, 2012) (Appendix 11). After formulating meanings, the next step was to review themes.

### 4. Reviewing themes

Initial themes were checked against the dataset, to determine those that gave a convincing description of the experiences and perceptions of the participants and their understanding of albinism, and those that answered the research question. Themes were categorised into sub-themes, combined according to their meaning/description and discarded if irrelevant to the research question (Appendix 12). It was at this point that data saturation (information power) was identified.

### 5. Emerging Themes

Detailed analysis of each theme was developed and the scope and focus were worked out while deciding on an informative name to be given for each theme (Appendix 13), and thereafter the final themes were sent to my supervisors for validation.

### 6. Writing up

After analysing the emerged themes, the analytic narrative and data extracts were weaved together to illustrate a story being told by the researcher about the data and a description given of participants’ perceptions, experiences and knowledge of the topic, making an argument in relation to the research question and contextualising it in relation to the existing literature.

### The researcher’s reflections

The researcher followed the strategy of “Not Knowing” in this study to prevent bias (Chan et al., 2013). Before commencement of the study, the researcher did a provisional literature review to identify a research gap and be able to defend her research proposal to the ethics committee and the institutional leaders of the research settings. The researcher did not do a robust literature review at this stage to prevent herself from being influenced by the knowledge gained from the published literature during the research process (Chan et al., 2013).

The research was well planned before implementation to prevent any inconvenience to gatekeepers or participants, therefore gaining access was not a problem and interviews were scheduled during working hours after participants had received their treatment.

A qualitative descriptive study design was a good choice because it allowed participants to voice their experiences, perceptions and understanding of albinism. The semi-structured interviews with open-ended questions helped the researcher to probe more and gain rich information from the participants. During data analysis, the researcher consciously put aside her knowledge to make sense of the information given by participants.

### **3.8 Rigour**

Rigour in qualitative research ensures that only information given by participants will be analysed to ensure a comprehensive summary of events in the everyday terms of those events as straight descriptions of phenomena (Sandelowski, 2000:334). An iterative data collection and analysis method ensures a recorded decision trail to enhance rigour (Koch, 2006). In this study to ensure rigour, bracketing was done, only questions related to the research question were asked and only statements made by participants were analysed.

#### **3.8.1 Trustworthiness**

Trustworthiness, a constructivist paradigm adapted from Guba and Lincoln (1989 cited by Koch, 2006), involves credibility, transferability, dependability and confirmability. Measures were employed to gain credibility, transferability, dependability and confirmability. Each of these measures is explained in accordance to the criterion they help to fulfil.

##### **3.8.1.1 Credibility**

To achieve credibility, only information given by participants was analysed. Only participants could evaluate and give a proper and true opinion of the results (Trochim, 2006). Participants were consulted telephonically as this was their preferred method of communication to confirm the contents of the final themes (member checking) and, they were all in support of the themes. Copies of transcripts were retained by the researcher.

### ***3.8.1.2 Transferability***

Refers to the extent to which results of qualitative research can be applied to other contexts (Trochim, 2006). To ensure transferability, research findings and assumptions that were most important to this study were carefully described from the participants' perspective to allow readers to decide on how they can apply the findings in their own situations (Trochim, 2006). The researcher made recommendations for the findings of the study to be tested further by other researchers (Colorafi & Evans, 2016).

### ***3.8.1.3 Dependability***

Dependability entails responsibility by researchers for describing changes which might occur in the research setting and how these changes affect the way the researcher approaches the study (Trochim, 2006). For the purpose of this study, I was committed to a thorough description of the methodology and data analysis from the commencement of the investigation to the completion of the study report. Limitations of the study have been recorded.

### ***3.8.1.4 Confirmability***

The published literature shows that researchers should return to participants to confirm that the analysed data represents their experiences (Shosha, 2012). In addition to achieving credibility of the data by contacting participants telephonically, confirmability of the data was also achieved, as all participants confirmed the accuracy of the researcher's analysis and they agreed with the themes extracted from their data. Finally cross-checking of the rigour and analysis was done by the research supervisors.

### ***3.8.1.5 Evaluation of the quality of the study***

To ensure transparency in reporting the study and to allow replication, reporting guidelines from the Equator Network (<http://www.equator-network.org/reporting-guidelines/coreq/>) were used to evaluate the quality of the study. To evaluate the quality of the semi-structured interviews the Consolidated Criteria for Reporting Qualitative Studies (COREQ), a 32-item checklist (Appendix 14) was used (Tong, Sainsbury, & Craig, 2007). The strengths of this study are reported in Section 5.5 of Chapter 5.

(O'Brien, Harris, Beckman, Reed, & Cook, 2014) The Standards for Reporting Qualitative Research (SRQR) (Appendix 15) were used to evaluate the quality of the completed study. A short summary of strengths of the study are reported in Section 5.5 of Chapter 5.

## **3.9 Ethical considerations**

The principles of the Declaration of Helsinki (WMA, 2013) guided the formulation of the protocol of this study. The protocol was evaluated and approved by the Faculty of Health Sciences Human Research Ethics Committees of the University of Cape Town and the National Committee on

Research in the Social Sciences and Humanities (NCRSH) of Malawi (Appendix 5) and (Appendix 7). The Declaration of Helsinki (2013) promotes respect for rights, health, dignity, integrity, self-determination, privacy and confidentiality of personal information of research subjects (WMA, 2013). The ethical principles are inter-related and some information overlap. The following principles were adhered to in this study.

### **3.9.1 Autonomy**

This principle promotes respect for human beings involved in the research and it acts as a basis for informed consent. Informed consent means that each individual participant should be given relevant information and participate voluntarily without being coerced. An informed consent form was designed (Appendix 2, 3) comprising an information sheet with details of the study and informing participants of my obligation to adhere to ethical principles. Speziale & Carpenter (2007) defined informed consent as providing adequate information to participants regarding the research, ensuring that they can comprehend the information and that they have the power of free choice enabling them to participate voluntarily or to decline participation.

During every interview session, the same information was explained as it was done for the recruitment process, consent was obtained from participants in writing, those who could not write were asked for a right thumb print using an ink pad and an independent person was asked to sign as a witness. The informed consent applied to interviews being digitally recorded and transcribed in order to use excerpts of interviews in the final reporting. Participants were informed that the researcher was a student for a Masters' degree under supervision and that the researcher had an obligation to discuss research findings with the supervisors to ensure trustworthiness of the enquiry. Mothers were informed that participation in the study was voluntary and that some of the questions could be sensitive and cause emotional stress to themselves and/or the child. To respect the mothers' autonomy, they were requested to bring a carer with them who could keep the child company in an area of the clinic that was safe, set aside for this purpose which was provided for in the letter of approval from the hospital (Appendix 1). If the child was an infant or toddler the mother's wishes to keep the child with her were respected. All mothers preferred to keep their children with them except for one who had two children, a toddler and a teenager both with albinism, so the toddler was sitting with her teenager sister in another room (Appendix 1). Participants were also informed that they may stop participating in the study any time they may want without any problems. By fully informing participants of all aspects of the study there was no deception.

### **3.9.2 Non-Maleficence**

This principle involves protecting the identity of the participants' and keeping their information (data) collected confidential. Confidentiality is a pledge that any information given by a participant

will not be published in a manner that identifies them (Speziale & Carpenter, 2007:66). Prior to the study, all participants were assured that names and anything that could identify them will be removed from data before publication in the dissertation or journal articles. Codes and pseudonyms were used to identify the participants. Audio recorded interviews were transcribed, transcripts were kept in locked computer only accessed by the researcher and the supervisors.

### **3.9.3 Beneficence**

Orb, Eisenhauer, and Wynaden (2001) described the principle of beneficence as doing good for others and preventing harm which can be inflicted on participants during the research process. The nature of this study did not involve physical harm but, asking a person to talk about experiences that were frightening, humiliating and/or painful could cause or increase anxiety and if this had occurred, interviews would have been terminated immediately after appropriate debriefing. During this study, no participant required counselling services despite prior notification of a health professional with additional training as a counsellor from the dermatology clinic department at the QUECH about the study, who would have been requested to attend to any participant who experienced emotional stress and had agreed to counselling. The benefits of the study, that is the importance of the objectives of the study, outweighed the potential risks.

### **3.9.4 Justice**

This principle refers to fairness and equal share (Orb et al., 2001) and entails that all categories of people should be subjected to benefits and risks of the research and that participants should only be excluded or included for reasons that have to do with the research question. The researcher had no prior relationship with any of the participants. Purposive sampling was used and participants were selected according to the inclusion and exclusion criteria set before data collection. This was a descriptive qualitative study therefore only words described by participants were reported.

### **3.9.5 Summary**

For this qualitative descriptive study purposive sampling of participants and semi-structured interviews were employed to obtain rich description of the experiences, perceptions and knowledge of mothers of children living with albinism. Ethical considerations and measures to ensure scientific rigour and trustworthiness were described in this chapter.

In Chapter 4 the findings of the study are described.

## CHAPTER 4 FINDINGS

---

### 4.1 INTRODUCTION

This study aimed to explore the experiences and perceptions of mothers of children living with albinism in Malawi and their understanding of the condition by employing a descriptive qualitative methodology. Data were collected from ten participants during face-to-face interviews in response to 12 questions (individual transcripts, Appendix 9) relating to their **Experiences (E) and perceptions (P) of these experiences:**

- 1.1E as a mother, can you share with me how you felt after seeing your baby for the first time after the birth?
- 1.1P Can you tell me the reason for such a feeling?
- 1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?
- 1.2P [If yes] What do you think may be the reasons for their reactions?
- 1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?
- 1.3P [If yes] what do you think could be the reasons for them to react that way?
- 1.4E as a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?
- 1.4P What do you think may be the reasons for this?
- 1.5. E How do friends, family members and neighbours treat you and your child now?
- 1.5P What do you think may be the reasons for this treatment?
- 1.6E Can you share with me any other difficulties/problems you have faced in raising your child?
- 1.6. P Can you tell me your thoughts about all what you went through?

Data were also collected from the participants in response to six questions relating to their **understanding of albinism** (individual transcripts, Appendix 9):

- 2.1 What is your own understanding of the cause of albinism?
- 2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?
- 2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?
- 2.4 Can you tell me where else you found information about albinism (for example friends, radio, television, family or community leaders) and the type of information?
- 2.5 Can you share with me your understanding of the information you found from these sources?
- 2.6 Can you share with me how you responded to this information?

Transcriptions by question are provided in Appendix 8. Data analysis of the interviews conducted was done at the end of each day.

## 4.2 Participant characteristics

Information power was achieved after interviewing ten participants. Age was not included on the data collection form but the inclusion criteria specified Mothers aged 18 years and older. Data on age was obtained from the patients' folders. The mean age of the ten participants was 33 years. It was observed that two of the ten participants themselves had albinism.

## 4.3 Findings from data analysis

Following the preliminary steps 1 (familiarising myself with the data) and 2 (coding), the next step was to search for themes and formulate meanings emerging from the data.

### 4.3.1 Searching for themes and formulated meanings

The codes and collated data were examined to identify significant common themes (potential themes) (Shosha, 2012). At this stage bracketing was maintained to ensure that formulated meanings described the participants' experience and perceptions from their perspective, not the researcher's presuppositions. Data in Table 4.1 illustrates how meanings were formulated from significant statements.

**Table 4.1: Significant statements and formulated meanings**

<b>Significant statements</b>	<b>Formulated meanings</b>
After my child was born the nurse told me that it was born with albinism and I accepted it without problems". Transcript 1, page 1 lines 1X1.	Mother indicates acceptance of her child born with albinism.
"This was because "this thing" does not happen often, so it was strange to them". Transcript 1, Page 1, lines 1X4	Mother believes that children born with albinism are rarely found and that it could be the first time that midwives delivered such a child.

Data in Table 4.1 show how the initial themes were checked against the dataset, to determine those that gave a convincing description of the experiences and perceptions of the participants and their understanding of albinism, and those that answered the research question.

### 4.3.2 Reviewing themes

Themes were categorised into cluster themes, combined according to their meaning/description and discarded if irrelevant to the research question (Appendix 12). It was at this point that data saturation (information power) was identified. An extract of the process is shown in Table 4.2.

**Table 4.2: Cluster themes and emerging themes from formulated meanings**

Formulated meanings	Theme clusters	Emergent theme
<p>Mother indicates acceptance of her child born with albinism. <b>Transcript 1, page 1 lines 1X1.</b> Mother indicates that she accepted her child with no problems <b>Transcript 3, page 5, line: 3X1.</b> Mother shows that nurses accepted her child. Mother indicates that motherly love helped her to accept the child at once. <b>Transcript 4, page 7, lines: 4X3.</b> Neighbours accept a child with albinism as any normal child. <b>Transcript 4, page 7, line: 4X10.</b> Mother indicates that motherly love helped her to accept the child at once. <b>Transcript 5 page 9, line: 5X2.</b> Mother perceive a child with albinism just like any human being. <b>Transcript 1 page 1, line 1X13.</b> Mother believes that her child with albinism is just like any human being despite a different appearance. <b>Transcript 8, page 16, lines: 8X13.</b></p>	<p><i>Acceptance</i></p>	<p><b>MOTHERS' IMPRESSION OF A CHILD WITH ALBINISM</b></p>

### 4.3.3 Emergence of themes

Four main themes emerged from the data namely: stigmatisation, harm and discrimination; mothers' impressions of albinism; mothers' awareness of albinism; and psychosocial effects of albinism. Within the themes sub themes emerged namely: EXPERIENCES - killings of people with albinism, labelling of people with albinism, rejection by family members, friends, neighbours and husbands. PERCEPTIONS of these experiences: acceptance, mothers' perceptions of health workers and societal reaction, paucity of information, awareness of the physiological causes of albinism, awareness of unavailability of and expense of sun protective products and implications on employment.

### 4.3.4 Defining and naming themes

After categorising themes into sub-themes and combining them according to their meaning, detailed analysis of each theme was developed and the scope and focus were identified while deciding on an informative name to be given for each theme (Appendix 13). Thereafter participants were consulted for confirmation of the themes and the final themes were sent to my supervisors for validation. Extracts of the process are shown in Tables: 4.3, 4.4 and 4.5.

**Table 4.3: Extracts for stigmatisation, harm and discrimination and Mothers' impression of having a child with albinism (Appendix 13)**

Main themes	Main categories	Significant statements
<b>Stigmatisation, harm and discrimination</b>	Killings	“Children with albinism deserve to be killed immediately after birth” 5X4
	Labelling of people with albinism	“Some people call her Napweri”. 6X8 “Husband and family not supportive “Mother divorced” 3X11
	Rejection by family, friends	“Being accused of cheating with another man”. 7X6, 5X5, 10X5
<b>Mothers' impressions of having a child with albinism</b>	acceptance	“God cannot create a bad thing”. 2X2 “I just felt that it was a gift from God” (4X8)
		“I thank God that I just accepted my child at once” (5X1).
	<b>Health workers' attitudes</b>	“Some friends and neighbours have suggested to me that hospital staff might have exchanged my normal child with the one with albinism”

#### **4.4 Main theme 1: Stigmatisation, discrimination and harm**

This theme describes participants' life experiences: what they have been through with their families, neighbours, and society at large in raising their children. The experiences were both positive and negative as described in the sub-themes.

##### **4.4.1 Sub-theme 1: Killings of people with Albinism**

Almost all the participants reported some kind of stigma and myth regarding albinism. Allawh and Norton (2014) indicated that since the year 2000, stigma resulted in 200 people with albinism in East Africa having been killed or body parts amputated. This qualifies the statements of two participants who testified that people had questioned mothers as to why they had not killed their children and also statements of other participants as reflected in the following quotes:

*“There are times when some people have said to me as to why I did not kill the child when he was just born” (4X11).*

*“Some of my friends have directly asked me as to why I did or do not kill my child and, I do not want to be anywhere close to them” (10X9).*

*“I was told not to worry and not do anything to the child because she is a human being. Because some people think of killing a child just because he/she is born with albinism” (8X13).*

*“Eish! I feel worried especially when I hear stories of people with albinism being abused and killed, I feel sorry for myself and scared. “I really feel scared but I put God first so that he should protect my child from people with evil thoughts who keep on following me without my knowledge” (1X11 & 1X12).*

Participants reported that they are mostly targeted because some people believe that private parts of people with albinism are a source of money and that is why they are killed and sold for rituals. This excerpt was extracted from the following sentences:

*“People call my child “makobiri” meaning money. They say my child can be a source of money if I sell her”.7X7 “I am also scared of those people who call my child “money” (7X12).*

*“I was also forced to put my child in a private school for safety reasons thou with difficulties in paying fees just to keep her on a nearer school to my area” (5X9).*

*“Just a day before yesterday, I was in the house and could not see him when I came out, when I asked his friends, I was told he was following another man who asked him to go with him. I run after them with my neighbour and the man suddenly disappeared. When I asked my child who the man was, he just said that the man told the child that he is” a bwana”, a Chichewa term meaning “sir”. This made me more scared than before (9X9, Fatima).*

#### **4.4.2 Sub-theme 2: Labelling of people with albinism**

Reports have indicated that people with albinism are segregated in various ways by being labelled as “others” due to societal beliefs that are used as a justification to protect themselves from death, curses, suffering and many evil things which are believed to be associated with albinism (Imafidon, 2017). For example, findings of this study have indicated that albinism is perceived as a contagious disease to the point that some people do not want to be close to a person with albinism for fear of being contaminated. This happens in schools, society and even on buses. Society has a belief that spitting or touching one’s hair can prevent an individual from getting albinism. One participant explained to the interviewer the reasons why people spit and touch hair when they see someone with albinism:

*“I love my child but other people spit out and some parents tell their children to touch their hair when they see her” (5X7).*

*“I think and I have heard that they do so to prevent their children from turning into a child with albinism” (5X8).*

Some participants reported that people think that people with albinism just disappear mysteriously like ghosts:

*“Maybe because they think a person with albinism is not a human being, does not live long, just disappear” (6X7).*

*“ I have once heard from friends that people with albinism just disappear, they do not die. “It made me realise that they were disappearing because they were killed or sold” (5X14 & 5X15).*

Mothers who give birth to children with albinism are mostly accused of being unclean or cursed due to a knowledge deficit regarding albinism (Masanjala, 2014). For example, one participant reflected on how some family members and some neighbours treated her child:

*“Some of them accepted him but some mocked me that how could I give birth to a child who stinks or smells like the sun? He is going to bring calamity to us”. Pregnant women also chase him, saying he will bring calamity “will make them deliver a child with albinism” (2X5)*

People with albinism are also mocked for not being human. For example, one participant seemed so emotional after narrating her story but refused counselling; saying she felt much better after talking to someone who could listen to her story without judging her. This excerpt is self-explanatory:

*“ I have been despised that I and my children resemble a pig”. “People say that they stopped eating pork because of me; that I resemble a pig” (6X6 & 6X1)*

Some participants mentioned common Malawian names used in mockery such as “Napweri” [meaning dry pigeon peas], “mzungu” [meaning white person] or “Makobiri” [meaning money]:

*“Some relatives call her names such as: Napweri, mzungu” (6X8)*

*“I get despised. People call her Napweri, hair like a “doll” and some friends isolate her” (8X6, 6X5)*

#### 4.4.3 Sub-theme 3: Rejection by family members, neighbours and husbands

Mothers and children living with albinism are not only rejected and stigmatised by community members but also within their families: Four participants reported that the husband's side of the family were unsupportive. Two participants explained their different experiences with their family and friends after giving birth to their first-born children with albinism:

*“Most of my relatives were disappointed though some supported me because in our family I was the first one to give birth to a child of this kind”. (1X5)*

*“Some people despise me that “how can I, a black mother give birth to a white child?” (8X8).*

*“You know people talk, some were laughing that they cannot bear and keep a child with albinism” (9X5)*

*“They accepted her but some were saying “look at the white person” we are going to sell her” (6X5)*

One of the misconceptions regarding albinism (Cruz-Inigo et al., 2011) is that a pregnant woman must have slept with a white man or, the devil must have replaced the normal child with the one with albinism and this also leads to stigma. This means that some people think that only mothers who have albinism (white in appearance) can give birth to a child with albinism. Out of ten participants in this study, eight were black in complexion and they were accused of infidelity after giving birth to their children with albinism as reflected in their sentences below:

*“The main challenge I have gone through is losing my marriage. My ex- husband's relatives were talking a lot because my husband does not have albinism so I decided to get out of marriage and take care of my child” (3X11 Ida).*

*“In my family, there was no mistake but my husband's family did not accept the child, they said I had slept with someone with albinism to give birth to the child. My husband sent me home to my parents for six months till they got back to their senses” (5X5 Catherine).*

*“My sister-in-law laughed and accused me of sleeping with another man with albinism” (7X5 Chrissy.)*

*“My family accepted my child and they still love him but my husband and his family did not accept the child and their relationship with the child is not good up to now” (10X5).*

*“The child's father and his family do not support him financially; he only is supported by my parents” (10X11).*

*“I have also been accused of sleeping with another man and my marriage is affected; my husband asked me to choose between marriage and his own child of which I chose my child. My husband said plainly that he does not want this child” (10X7).*

One of the participants who was black in complexion said that her husband was the same. She reflected how her own mother reacted after seeing her baby for the first time:

*“I remember my mother was shocked with the appearance of my child and was just showing everyone in the room. Saying “look at the appearance of this baby.” but I told her that it was what God gave us. (7X5)*

Hong et al. (2006) made it clear that people with albinism endure segregation from society and sometimes they isolate themselves for fear of being abused. This qualifies statements of some participants who reported that due to the stories of attacks, killings and selling of people with albinism, they do not trust anyone at all:

*“I believed the story and I always hold my child by the hand when going anywhere: church, school or market” (9X5). “I realised that I cannot even trust my neighbours because they can turn against my child anytime” (9X6).*

Participant 06X was the oldest of all the participants and mentioned something related to her oldest daughter which is reflected in the statement below. 9X15

*“I have another 18-year-old girl but she fears to date a normal man because she does not trust anyone” (6X6).*

## **4.5 Main theme 2: Mothers’ impressions of having a child living with albinism**

The theme explains how mothers of children felt after seeing their children for the first time and how they felt about them on a daily basis. They also expressed how they expected other people to treat their children. All mothers expressed love for their children although not all mothers accepted their child born with albinism straight away.

A discussion of each sub-theme follows:

### **4.5.1 Sub-theme 1. Acceptance**

Participants emotionally narrated their stories as reflected below:

*“My understanding is that, this child is the same as any other child and deserve love and care from me and his father”. “There is no difference between a person with albinism and any other person because when injured, we feel the same pain” (1X13 &1X17).*

*“I just felt that it was a gift from God” (4X8).*

*“I thank God that I just accepted my child at once” (5X1).*

*“I was happy because that was what God gave me” (7X1).*

*“I always tell him that “we are the same; we both have arms and that your friends are just jealous of your appearance” (10X15).*

*“I can tell him that he is different from other children because that is how God created him” (1X15).*

*“I felt pain. But later on, accepted that it is God’s creation, it is what God gave me” (6X1 Doreen).*

*“It was so painful being my first child, eventually I accepted the child”. “It was because of the gospel message that came on time, teaching about different gifts that people receive from God” (10X1 Fanny).*

Two participants reflected on what they heard on a Malawian radio broadcast regarding discrimination of people with albinism and how the message helped them accept their children with the same condition:

*“I heard from the Malawi broadcasting radio that people with albinism are human beings, they should not be isolated” (6X15).*

*“I heard from the radio that people with albinism are also human beings, we should love and not isolate them” (.8X15).*

It also appears that some neighbours, relatives and friends understood the fate of a child living with albinism as they showed love and support to mothers of children with albinism and their children born with albinism:

*“Some neighbours are good; they help me to take care of the child and advise me not to leave the child alone. One of my neighbours has a child with albinism and she is the one who informed me that free sun cream is provided at Queen Elizabeth Central Hospital dermatology clinic” (Fatima. 9X7).*

*“I have no problem with my neighbours” (4X9 Agi). “They do not differentiate between a child with albinism and a normal child” (4X10 Agi).*

*“All friends and relatives show love to this child” (Ida. 3X9).*

*“Yes, I remember when he was born everyone was happy to see him, no one looked surprised”.*

Some participants expressed how they felt about their children born with albinism as God’s creation just like any other human being, and prayed for their success in life to shame people who think there is no potential in a child with albinism. Participants shared their experiences and perception as reflected in the sentences below:

*“It is my prayer that this child grows into a responsible person to put into shame those who despise her” (5X10) Catherine.*

*” My understanding is that a child with albinism is just like any person” (2X13 Martha).*

*” A child with albinism is just like any other child provided you follow advice on how to care for him” (4X13).*

*“A person with albinism is a human being just like anybody, we only differ in complexion” (8X13).*

#### **4.5.2 Sub theme 2: Mothers perceptions of health workers’ attitudes**

One participant explained how she felt about nurses and midwives who just went straight to her mother/guardian immediately after the birth of her child to ask what to do about the baby before communicating with her. The participant stated that those nurses and midwives in the labour ward made her think that they might have been helping mothers to kill their children born with albinism. The participant also stated that she felt left out by nurses and midwives in the decision making of the welfare of her own child. This theme was reflected in the following statements:

*“They did not say anything to me or show me my baby but went straight to my mother and asked what they should do with the baby without my knowledge” (5X3).*

*“In my mind, I think they may be some people who ask midwives to kill their children when they are born with albinism; maybe that’s why nurses were seeking permission on what to do with my child” (Catherine 5X4).*

There seems to be rumours in some communities of some health workers being involved in exchanging babies born with albinism in labour wards, stealing and killing of people with albinism, and that some hospitals supply free sun cream to attract people with albinism so that they can sell or kill them. One participant shared her story while another participant disapproved of what some of her neighbours and friends thought of health workers:

*“Some neighbours have been discouraging me from going to the hospital for sun cream, they believe the hospital people have evil plans so they are attracting people with free sun cream. Surprisingly, this is the sixth year I have been coming and nothing has happened to my child” (10X9 Fanny).*

*“Some friends and neighbours have suggested to me that hospital staff might have exchanged my normal child with the one with albinism” (7X7).*

Some participants mentioned that albinism is not common that is why some nurses were surprised to see a child born with albinism; it may be a strange condition to the nurses and midwives as well:

*“This was because “this thing” does not happen often, so it was strange to them” (1X4).*

*“I think they were surprised because it could be their first time to deliver a child with albinism and also to see a child with albinism with no skin rashes or black spots” (2X4).*

*“They looked surprised but did not tell me anything” (6X3).*

*“The midwives were surprised and said “the child is a human being but different from other children” (8X3).*

#### **4.6 Main Theme 3: Mothers’ awareness and understanding of albinism**

**Table 4.4: Extract from Appendix 13 naming and defining “awareness”**

<b>Main themes</b>	<b>Main categories</b>	<b>Significant statements</b>
Mothers’ awareness of albinism	Paucity of literature.	“I was not told why I gave birth to this kind of a child” (1X15 Chair).
	Lack of clarity of the physiological causes of albinism	“Albinism is caused by a problem found in a woman or man”. 1X16 “Albinism is caused by some paint found in the abdomen”
	Role of local radio broadcasts.	Awareness of safety precautions from community leader and” Radio Malawi”
	Awareness of unavailability and expense of sun productive products.	Inadequate supply of sun cream makes her spend a lot of money due to multiple trips to the hospital within a short period of time.
	Awareness of poor site	Visual challenges

The theme “mothers’ awareness of albinism” is the third main theme which explains how participants understood albinism as a condition, its causes, and problems associated with it as well how to prevent those problems.

#### **4.6.1 Sub theme 1: Paucity of information on the real cause of albinism**

Participants did not have any information on the cause of albinism and five participants indicated that they had no idea about what causes albinism as summarised in the following statements:

*“I was not told anything when my child was born and I am not sure if my mother was told anything when she first came to the clinic to collect sun cream because I was sick and she came on my behalf” (9X12 Fatima).*

*“Like I said earlier on, I was just told that the child was normal; there was no any problem with him” (10X12). “I always ask myself a question of what exactly the cause of this is” (10X1). “I do not know or understand what exactly happens and I always ask myself that same question” (10X12, 10X13 & 10X14, fanny).*

*“I delivered through caesarean section and do not remember being told anything after waking up”. “I was told nothing by the nurses, doctors after my child was born” (7X3 & 7X14 Chrissy).*

*“I can tell him that he is different from other children because that is how God created him, I cannot say much because at the hospital, I was not told why I gave birth to this kind of a child” (1X15 Chair).*

#### **4.6.2 Sub theme 2: Lack of clarity on the physiological causes of albinism**

Findings revealed poor understanding of the cause of albinism. Five participants gave different versions of the causes of albinism. For example, participant 06X explained that albinism is caused by a problem found in a man or woman:

*“I remember one day, I just heard on the radio, that for a child to be born with Albinism, there is a small problem found in a woman or man but I did not hear properly because I got there when the programme was almost finished” (1X16 Chair).*

One participant reflected on what she was taught by health professionals after the birth of her child with albinism. She was the only participant who reported that she got information from a health professional:

*“I was told that my child had weak genes and failed to develop the top layer of the skin but he is just as any other person. I was given an example that if a normal person has an open wound, a white skin appears first before blood comes out. That is what I grabbed” (3X14 Ida).*

Another participant shared her understanding of the cause of albinism which clearly indicated misunderstanding of the facts:

*“I just heard that its gee... or blood that resembles what....? Thus, what causes albinism but we are the same only that they lack the skin that protects them from the sun” (5X11 & 5X12 Catherine.)*

The study revealed societal beliefs that albinism is caused by “Mwanamphepo” [taboo, that is, if a pregnant woman develops a skin disease, she will give birth to a child with albinism]. This excerpt is reflected in the statement of Participant 09X:

*“Let me just say people say it is caused by “Mwanamphepo” (9X11)*

Participant 07X also reflected on her understanding of what causes albinism:

*” I just heard that there is some paint in the abdomen. but I have forgotten its name which, it is found in men, and when it is in large amount. I don’t know what happens but, it can cause albinism” (7X13*

#### **4.6.3 Sub-theme 3: Role of local radio broadcasts**

Most participants in this study mentioned that the Malawi Radio Broadcasting Corporation (MBC) played a big role in promoting awareness of albinism. and this was their main source of information. Some participants reported that they had learnt of the killings and attacks associated with albinism and safety precautions on how to protect themselves and their children with albinism from the MBC radio broadcasts. Participants shared their different stories with the researcher as follows:

*“Yes, I do hear from the radio that we should not let our children move alone, because some people can kill them. I just heard from the radio a day before yesterday that a boy went missing on Independence Day (6/7/2018) and was found dead and the police are suspecting the step father but both parents are arrested. It is scary” (9X14).*

*“I just heard from Malawi Broadcasting Radio that we should take care of our children, they should not be walking alone, and I always follow my child wherever she is playing” (2X16). It’s like I am also playing to ensure his safety. My child is also affected because sometimes he refuses to go to school for fear of being killed” (2X17).*

*” Sometimes our community leader calls for a meeting for all people with albinism to advise us that we should not walk at night nor open the door for anybody at night”. “I also heard on the Malawi broadcasting corporation radio yesterday that the chairperson of our association was found dead and buried but the police is still investigating” (7X16).*

Participant 05X reflected on what she has heard from the radio and friends in the sentence below:

*“I have once heard from friends that people with albinism just disappear, they do not die. I have also heard from the radio that other people think people with albinism are a source of wealth as such they kill them or sell them. I heard from friends that someone sold her own sister’s daughter. I have also heard that some people come like thieves at night but just to steal a child with albinism and nothing else” (5X14).*

#### **4.6.4 Sub-theme 4: Awareness of unavailability and expense of sun protective products**

Some participants complained of an inadequate supply of sun screen lotion which made them spend a lot of money due to multiple trips to the hospital within a short period of time. They suggested that it would have been better if they were given enough stock to last a long time.

Quotation taken from participant’s statement:

*“In terms of sun burn cream, we are not given enough supply sometimes it does not last till the next appointment day, we spend a lot of transport coming to collect sun cream, if they could consider giving us enough maybe it could be better” (7X11).*

Participant 09X said that she spent money buying cream/lotion which she was supposed to get for free if she was informed. She also said sometimes she has transport money issues as reflected below:

*“I also have been buying sun cream small tube at MK3,500 and large tube at MM7,000 from a colleague with albinism not knowing it is given for free at Queens Hospital. I have financial problems sometimes struggle to find transport money when going to collect sun cream”.*

Although all ten participants acknowledged awareness of the physical problems associated with albinism and sun protective measures since the birth of their children, three participants indicated that they only knew about sun protective measures and where to access free sun cream at a later stage (Appendix 8).

Excerpts extracted from three participants’ interviews:

Participant (06X) expressed concern that nurses and midwives just looked at her and did not tell her anything regarding albinism until at a certain age of a child when she was informed about sun protective measures.

*“I was told nothing at the hospital regarding albinism after giving birth”. “They looked surprised but did not tell me anything. I was only told how to care for my child at a certain age at the under-five clinic” (6X3 & 6X13 Doreen).*

Participant 07X reflected:

*“I was told nothing by the medical people, they just sent me to cotton weaving company where I got information on how to care for my child” (7X14 Chrissy).*

#### **4.6.5 Sub-theme 5: Awareness of poor sight**

A few participants seemed to understand some of the physical problems associated with albinism such as poor sight and they were able to negotiate with school teachers to assist their children who had visual challenges:

*“He also does not see properly but I requested the teacher that maybe he should make his writings a little bigger” (10X11 Fanny).*

*“She has vision problems and I cannot afford glasses but the teacher helped by putting her in front to read easily on the board” (8X10 Lines).*

### **4.7 Main Theme 4: Psychosocial effects of albinism**

**Table 4.6: Extracts of psychosocial effects**

Main theme	categories	Significant statement
Psychological effects of albinism	Feeling of loss of esteem.	Disappointment after giving birth to a child with albinism 2X1
	Pain, shame and anger	Being accused of cheating with another man. 7X6, 5X5, 10X5
	Implication on employment	Struggles to get a job of her scope Refusing to go to school may lead to no proper employment (2X11)

This theme describes social and psychological problems encountered by participants in raising their children born with albinism. Under this theme two sub-themes emerged: 1) feeling of loss of esteem and 2) implications for employment.

#### **4.7.1 Sub-theme 1: Feeling of loss of self-esteem**

A few mothers who had given birth to children with albinism felt devalued and were accused by their husbands and family of sleeping with another man as the cause of giving birth to a child with albinism, resulting in them experiencing pain, anger, emotional trauma and low social esteem. Some participants reflected on the feelings they had after giving birth to their first child with albinism:

*“I was disappointed because I got pregnant and left school and only to give birth to “this kind of a child” but I also remembered that God cannot create something that is untrue” (2X2).*

*” I was so disappointed when I saw the child but my mother encouraged me that God cannot create something that is bad, I later accepted” (2X1).*

*” The six months separation from my husband was very painful to me and being accused of a thing I did not do (sleeping with another man with albinism) was a disgrace to me (5X9).*

*“It pains me a lot”. (6X11).*

*“May be its because of their understanding, they do not see the importance of a person with albinism” (4X8)*

#### **4.7.2 Sub-theme 2: Feeling of pain, fear and emotional trauma**

One participant expressed her reasons for being worried after seeing her baby for the first time:

*“Let me say, I was worried about where I was going to get sun cream, because I see children of this kind develop sores on their skin” (9X1).*

*“It was so painful being my first child, eventually I accepted the child” (10X1). “I am so scared but I keep on Praying with my mother for protection and we encourage each other” (10X18) “I do not sleep normally as you people do. I am scared especially at night thinking of what might happen when I am asleep. I have met a colleague at the clinic who was stabbed all over as he was trying to protect himself from people who wanted to cut his private part but failed because he fought with them and that... makes me more scared at night. I have also been accused of sleeping with another man and my marriage is affected; my husband asked me to choose between marriage and his own child of which I chose my child. My husband said plainly that he does not want this child” (10X7).*

### **4.7.3 Sub-theme 3: Implications for employment**

It appears that people with albinism struggle to find employment despite having good qualifications more than those without albinism because employers perceive them as unproductive and this affects them psychologically:

*“I have another 18-year-old girl she struggles to get a job despite having a Malawi School Certificate of Education. “May be because they think a person with albinism is not a human being, does not live long, just disappear” (6X7).*

In their study Braathen and Ingstad (2006 cited by Brocco, 2015) reported that without proper education, people with congenital problems, both male and female cannot aspire to employment other than cultivating their own lands or being hired by others to do manual jobs while being exposed to the sun. This means that when children with albinism refuse to go to school due to the abuse and challenges they face, they stand a higher chance of no employment in future with its financial challenges:

*“The challenges are: sometimes friends refuse to play with him, saying that he smells like sun, he is a “Napweri” [dry pigeons]. This make him refuse to go to school” (2X11).*

## **4.8 Summary of Findings**

The ten participants described their experiences, perceptions and understanding of having children living with albinism. Four central themes emerged from the data: Stigmatisation, discrimination and harm; Mothers’ impressions of having a child living with albinism; Mothers’ awareness and understanding of albinism; and Psycho-social effects of albinism. Sub-themes emerged from the central themes.

Sub-themes that emerged for stigmatisation, discrimination and harm were: killings of people with albinism; labelling of people with albinism; and rejection by family members, neighbours and husbands.

Sub-themes that emerged for Mothers’ impressions of having a child living with albinism were: acceptance; and their perceptions of health workers’ attitudes.

Sub-themes that emerged for Mothers’ awareness and understanding of albinism were: paucity of information on the real cause of albinism; lack of clarity on the physiological causes of albinism; role of local radio broadcasts; awareness of unavailability and expense of sun protective products; and awareness of poor sight associated with albinism.

In the following chapter, the findings are discussed in relation to published literature on the experiences, perceptions and understanding of mothers who have children living with albinism. Strengths and limitations of the study are discussed followed by the recommendations and conclusions drawn from the study.

## **CHAPTER 5 DISCUSSION, STRENGTHS, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION**

---

The study objectives were achieved. First, to describe the experiences and perceptions of mothers of children living with albinism in Malawi and second, to describe these research participants' understanding of albinism. Chapter five provides a discussion of the main findings from the research and where applicable, links the literature to the study findings, particularly grounded in a review of the literature as presented in Chapter Two. Limitations and strengths of the study have been addressed and recommendations made for nursing education and other educational institutions, nursing practice, government, society and social media.

Analytical and critical thinking has been attempted in relation to the main themes that emerged from the data:

- Stigma, discrimination and harm associated with albinism
- Mothers' impressions of having a child with albinism
- Mothers' awareness and understanding of albinism
- Psychosocial effects of albinism.

### **5.1 Stigmatisation, discrimination and harm**

#### **5.1.1 Killings and labelling of people with albinism**

People living with albinism are stigmatised (Hong et al., 2006) and discriminated against (Cruz-Inigo et al., 2011) as found in the present study. Mothers were worried about the safety of their children due to reported attacks and killings associated with albinism. It is reported that children with albinism have also been targeted for killings and attacks by those practising witchcraft and body parts are sold to traditional healers for local medicine "muti" or kidnapped (Cruz-Inigo et al., 2011). Two study participants testified that some people asked them directly why they kept their children alive. Allawh and Norton (2014) reported that 200 people with albinism in East Africa had been killed or body parts amputated due to stigmatisation since the year 2000. One participant in the present study narrated a story of a colleague she had met at the clinic who was stabbed by people attempting to amputate his private parts.

Myths and stigma result from lack of awareness of albinism (Baker et al., 2010). The present study has generated knowledge which supports the existing literature that misunderstanding of albinism in Malawi and many African countries has led to discrimination, abuse and killing of people with albinism. Stories have been narrated of people living with albinism being mocked and referred to as

ghosts, 'Napweri' [dry pigeon peas], 'mzungu' [white person] and 'Makobiri' [money]. Participants reported that they feared for their children who are mostly targeted.

Stories have been told by many researchers of children being abducted from their homes at night, or on their way to and from school. Brocco (2015) reported that in Tanzania, a special boarding school was created to protect children with albinism who had been abused, abducted and killed. Stories of mothers' suffering and fear for their children have been reported by many researchers. Cruz-Inigo et al. (2011) reported that mothers had been attacked by a group of criminals wielding machetes in an attempt to get to their children who had albinism. The present study reported that mothers lived in fear especially at night. Baker et al. (2010) reported that some people using public buses and other communal places did not want to sit close to a person with albinism for fear of 'catching the disease'. In the present study participants described how some people touch their hair when they see a person with albinism to prevent themselves from getting albinism.

Spitting is a common practice when a person with albinism is seen and this is particularly done by pregnant women while touching their abdomen, believing that by doing so, their unborn child is protected from albinism (Baker et al., 2010). One participant described how people spat after meeting a person with albinism, believing them to be spirits or ghosts who disappear mysteriously. This information supports the existing knowledge which suggests that people with albinism are believed to be ghosts of the dead who return to earth as new babies. People threaten their children to stay away from these 'ghosts' which entrenches the stigma that children with albinism face from friends (Imafidon, 2017). A study conducted in Zimbabwe, (Machoko, 2013) found that people with albinism are considered to be water spirits.

People with albinism are not always accepted in an African community nor in a white community, because despite being white in colour, they also possess features of a black person, and society does not know how to identify them therefore they are discriminated against (Phatoli, Bila & Ross 2015). A study conducted in Malawi between 2010 and 2011 indicated that the very visible difference in appearance of those living with albinism can lead to lack of acceptance and a poor social life (Lynch et al., 2014). A study conducted in Tanzania in 2014 to assess the population's level of awareness of albinism and of the predicament faced by members of their households, revealed that people with albinism are considered disabled and marginalised (Masanjala, 2014).

Phatoli et al. (2015) found that some people with albinism were ready to befriend people with albinism but not to the point of dating them as found in this study, while Baker et al. (2010) argued that sometimes people with albinism may be accepted by their partners but face challenges with their partner's family members. Stigmatisation can be counteracted by raising awareness about albinism, advocacy through the media and engaging community leaders in changing society's attitude (Fayoyin & Ihebuzor, 2014).

## **5.2 MOTHERS' IMPRESSIONS OF HAVING A CHILD WITH ALBINISM**

### **5.2.1 Acceptance and rejection by family members and husbands**

Some participants described the love and support they received from family members and their prayers were valued. Baker et al. (2010) reported that children with albinism are judged by their appearance but when they are left to realise their potential, they can succeed in life. Similarly, Tandon (2016) described a person with albinism being as healthy as any other person considering that albinism 'itself' does not cause mortality. In the present study, one participant reported that she kept on praying for success for her child so that one day those who think there is no potential in children with albinism would be put to shame. George and Duquette (2006) described a case study of a grade six pupil with cutaneous albinism and poor vision who progressed academically because he was supported mostly by his mother and was given a chance to explore his potential by exposing him to many activities. Brocco (2015) reported that many parents believe that albinism is the will of God and no one can question God since he is the primary source of creation. Almost every mother in the present study expressed great love and acceptance of their children with albinism although for some mothers this took time. These findings are also in line with what Braathen and Ingstad (2006) found in their study conducted in Malawi that explored attitudes and beliefs and where mothers expressed love for their children believing that they are a gift from God.

In contrast, Masanjala (2014) reported that mothers of children with albinism were rejected by their families who believed that they are not human beings thereby increasing the mothers' fears. Fathers of children with albinism reportedly abandoned their wives for deciding to keep their children (Baker et al., 2010). In the present study some men asked their wives to choose between their own child and the marriage. Four participants described the abuse they experienced at the hands of their husbands, one of whom was separated from her husband but had been reunited after six months.

The literature reviewed from Malawi and other African countries revealed that mothers who have children with albinism and the children themselves are more abused than those who do not have albinism due to their vulnerability. The present study findings of accusations of mothers of sleeping with men from other races or with men with albinism, misconceptions that only people with albinism can give birth to children with albinism, marriage separations and divorces support the existing literature. Kimbassa, (2016) described that most women are blamed due to male dominance in African countries and that when a father has ocular albinism, he appears normal with a black skin and is not aware that he is carrying the albinism gene. When a man with ocular albinism marries a woman with ocular albinism who is not aware of it, the couple is likely to give birth to a white skinned child. The author further reported that the father is the first to deny his contribution to the albinism and blames the mother for this. Four participants in the present study reported being

abandoned by their husbands, some for a period of time and some permanently just because mothers gave birth to children with a white skin colour.

In the present study some family members expressed disappointment at the birth of a child with albinism as there was no family history of albinism. Kimbassa (2016) and Franklin (2018) found that mothers of children are blamed for the condition of their children, accused of sleeping with other men and being cursed which leads to financial problems, since most mothers raise their children with no support from their fathers. Children are therefore deprived of education and good healthcare services. Similar results were also reported in a study carried out in South Africa and Zimbabwe to trace myths and their impact on people living with albinism (Baker, 2010).

A study done in Tanzania indicated that many children are raised by single mothers because fathers often abandon women who give birth to children with albinism and this leads to poverty and exclusion of the abandoned mother (Baker et al., 2010). In line with published literature participants who were abandoned by their husbands (fathers of their children) reported having financial challenges in raising their children on their own. Bos et al. (2013) reported that people who are related to a person with a stigmatised condition experience low social esteem and try to hide their kinship which could be one of the contributing factors that fathers abandon their own. This knowledge will contribute to providing improved genetic counselling by nurses and other health professionals.

### **5.2.2 Health workers' attitudes**

The present study has generated information about mothers' perceptions that currently registered nurses and midwives are suspected of being involved in killing children with albinism at birth in labour wards in Malawi. This data is not supported in the available published literature. However, there is limited published literature about traditional midwives killing children who have albinism and presenting these as a stillbirth (Cruz-Inigo et al., 2011). One participant in the present study suggested that healthcare workers in clinical settings attended by patients with albinism are suspected of being involved in stealing and killing them by attracting them with the much sought after and scarce sun protective cream. No published scientific literature was found to support this perception. Some health professionals perceive albinism as being infectious due to lack of understanding of the cause of the condition (Cruz-Inigo et al., 2011).

## **5.3 MOTHERS' AWARENESS AND UNDERSTANDING OF ALBINISM**

Participants described their understanding of the cause of albinism, what medical professionals told them about albinism after the birth of their child, how they would explain their child's white

appearance and poor eyesight to their child, the type of information they found about albinism, where they found the information, and their understanding of the information and how they responded to this information.

### **5.3.1 Paucity of information on the cause of albinism**

Baker et al. (2010) reported that mothers who give birth to children with genetic conditions are supposed to receive genetic counselling and an explanation of the condition from nurses or doctors who have these skills and knowledge. Information should be imparted gently to the mother of the baby first by recognising the joy of having the baby and only then mentioning that the baby has albinism and the reason for the pale or white appearance (Baker et al., 2010). Furthermore, nurses empower mothers of such children by explaining the cause of albinism and how to take care of their children so that they can cope when they go home (Cruz-Inigo et al., 2011). Braathen and Ingstad (2006) reported that in their study no participant was able to explain anything related to the cause of albinism when asked to explain what they were told by medical professionals at the hospital. Similarly, in the present study participants reported not being given any information regarding the cause of albinism by any doctor, nurse or midwife after giving birth to their children. Only one participant was able to explain what she remembered, that is, *“I was told that my child had weak genes and failed to develop the top layer of the skin but he is just as any other person. I was given an example that if a normal person has an open wound, a white skin appears first before blood comes out”*.

Some participants indicated a lack of awareness of the cause of albinism by giving their own version of the causes “paint found in men’s abdomen”, “problem found in man and woman”, “mwanamphepo” [an ancestral skin condition which is believed to cause disease in new-borns if the mother has the condition when giving birth]. Phatoli et al. (2015) found that three of ten participants had no idea about what albinism is, five had some knowledge from the media but without fully understanding the cause of the condition while only two demonstrated knowledge of the condition.

Cruz-Inigo et al. (2011) reported a survey conducted in Zimbabwe which revealed that many children living with albinism did not know what caused their condition, instead they presented stories implicating witchcraft, God’s responsibility, punishment secondary to one of the family members mocking a person with albinism and many other incorrect causes. Similarly, two of ten participants in the present study reported that when their children asked them why they look different from their friends and parents, the participants told their children that they are white people or Indian and the children believed this. The remaining participants stated that they told their children that God made them as they are and they therefore grew up not knowing the cause of their condition. Cruz-Inigo et al. (2011) recommended that parents and children need to be educated on the cause of their condition

and its many medical and psychological effects to prevent members of the family thinking that the child is from unknown ancestors.

Lack of awareness is not restricted to the public and even health professionals lack understanding of albinism due to its relative infrequency (Baker et al., 2010). Some participants reported that the midwives were shocked when they saw their babies for the first time.

### **5.3.2 The role of local radio broadcasts**

Participants in the present study indicated that they had heard safety precautions on the MBC radio for the benefit of people living with with albinism in an attempt to prevent them from being abducted and killed. Only one participant mentioned the effort provided by a local community leader. This supports the literature suggesting that raising awareness through radio broadcasts and school curricula might be helpful in dealing with superstitions that exist regarding albinism (Cruz-Inigo et al., 2011)

### **5.3.3 Awareness of unavailability and expense of sun protection products**

In the present study, participants reported that they are supplied with free protective sun creams although two participants complained that an inadequate supply is provided and does not last long so they end up spending money making multiple trips to collect more sun cream. Sun cream is only supplied regularly by the central hospitals and occasionally in district hospitals and the distance is inaccessible for parents who are economically challenged. No participant reported being supplied with sun protection clothing. In line with the findings of the present study Cruz-Inigo et al. (2011) reported that the government should ensure that people with albinism are provided with skin protective measures, adequate assistance and funding by organisations involved in promoting albinism awareness.

Cruz-Inigo et al. (2011) reported that some people with albinism cannot afford to access health services due to poverty. Franklin et al. (2018) reported that people with albinism have rights such as protection of life including access to eye and skin care services and provision of sun protection materials. The authors recommended preventative measures such as early skin examination in children with albinism because of the high risk of developing skin cancer. Findings from the present study support those of Phatoli et al. (2015) that most people with albinism are economically challenged due to no employment and recommended that society and government need to implement measures to assist people with albinism to access sun protection measures.

### **5.3.4 Awareness of poor eyesight**

Bradbury-Jones et al. (2018) indicated that albinism adversely affects vision causing photophobia, squint and rapid involuntary movement of the eyes resulting in poor vision and most children cannot afford health services due to financial challenges. Similarly, Brocco (2015) indicated that many children with albinism experience eye problems such as photophobia, uncontrollable movements and poor sight. In this study, two participants indicated that their children had eyesight problems.

Franklin et al. (2018) reported that children with albinism have the right to education and attention must be given to ensure that they have support such as visual aids in mainstream educational settings. In the present study alterations in the classroom setting in mainstream schools helped the learners with albinism to cope with their poor vision. In contrast, the existing literature suggests that parents of children with albinism preferred sending their children to residential resource teaching centres where their academic needs were accommodated and not to mainstream schools where their children were stigmatised (Lynch et al., 2014). Similarly, Brocco (2015) found that schools are another social setting where children with albinism face stigma from friends and teachers. Students with albinism who have low vision can participate in mainstream schools as long as appropriate measures such as wearing glasses are taken (Phatoli et al., 2015). Franklin et al. (2018) reported that children have a right to education and teachers need to be supportive.

## **5.4 PSYCHOSOCIAL EFFECTS OF ALBINISM**

### **5.4.1 Feeling of loss of self-esteem**

One participant reflected on the feelings she had after giving birth to her first child with albinism: that is, *“I was disappointed because I got pregnant and left school and only to give birth to “this kind of a child” but I also remembered that God cannot create something that is untrue”*. Bos et al. (2013) described internalised stigma as a feeling of loss of self-esteem which is accompanied by psychological distress experienced by people who possess a stigmatised condition due to the discrimination they encounter from society. In this study some participants expressed the feeling of being devalued after giving birth to a child with albinism.

### **5.4.2 Pain, anger, shame and emotional trauma**

Genetic counselling is very helpful to women who have given birth to a child with albinism or any genetic condition. Baker et al. (2010:171) reported a scenario of a woman in Venda, South Africa who was ashamed of her baby and used to hide her until she received genetic counselling: ‘after genetic counselling the woman was able to take her child out because she was able to explain the genetic cause of the condition of her child’ (Baker, 2010:171). Likewise, in the present study three

women expressed feelings of shame, anger, pain and emotional trauma because they had no information and confidence to defend themselves against their husbands, families and society when accused of infidelity as a cause for giving birth to children with albinism.

### **5.4.3 Implications for employment**

Watson (2012) reported that stigma causes psychological effects which lowers an individual's self-esteem which may affect academic progress, mental health and professional achievement. In the present study, some participants reported that their children refused to go to school because of the treatment they got from friends and some teachers.

Braathen and Ingstad (2006) reported that people with albinism face employment challenges because it is believed that they die young, while Brocco (2015) argued that because of poverty, most people with albinism face academic challenges which then leads to no proper employment. Lynch et al. (2014) recommended that governments should support parents in decision making regarding their children's education and future employment prospects. Baker et al. (2010) reported the case of a woman with albinism in Bulawayo who, despite having the proper qualifications, was not employed because she was told that she was unattractive. The authors also reported the case of a man who was denied employment and his application was ripped up in front of him. In the present study, one participant reported that her daughter struggled to find a job related to her qualification while friends with the same qualification were employed. Stories of children refusing to go to school for fear of being stigmatised by friends have been told and this may have an impact on future employment future.

## **5.5 Strengths of the study**

At the commencement of the study there was no published or available literature specifically on the experiences and perceptions of mothers of children living with albinism in Malawi nor their understanding of the condition. This descriptive qualitative study and thematic analysis of the data has provided a scientific report to fill a gap in the existing literature.

To ensure transparency in reporting the study and to allow replication, reporting guidelines were used to evaluate the quality of the study. To evaluate the quality of the semi-structured interviews the Consolidated Criteria for Reporting Qualitative Studies (COREQ) Tong, Sainsbury, and Craig (2007) were used and the Standards for Reporting Qualitative Research (SRQR) were used to evaluate the quality of the completed study (O'Brien, Harris, Beckman, Reed, & Cook, 2014).

## **5.6 Limitations of the study**

Ethical approval took longer than expected, having to be obtained from the University of Cape Town and the ethics committee in Malawi for safety and statistical purposes before permission was granted by the hospital.

The similarity between Q1.4.E and 1.6.E resulted in little variation in participants' responses and these questions could have been merged. Selection of participants by the health professional at the dermatology clinic might have excluded participants who could have provided a different perspective. Limiting the study to a short period for data collection of 3 weeks might have limited the depth and richness of responses. Limiting the study to mothers and not to health professionals in the dermatology clinic or even to community members might have limited the usefulness of the study data. Telephonic rather than face-to-face discussions to achieve rigour might have limited dependability and credibility of the analysed data for emergence of themes.

Backward and forward translation between English and Chichewa for the interview guide, information sheet and consent form as well as for the transcriptions was time consuming and fraught with logistical difficulties. Thematic analysis involves identifying and describing meaningful ideas other than just writing statements (Alhojailan, 2012), and this is time consuming.

## **5.7 RECOMMENDATIONS**

Broad recommendations are made aimed at reducing stigma and problems encountered by mothers of children living with albinism in Malawi. Lack of awareness of the cause of albinism and discrimination have been found to be the main problems experienced by participants in this study. Mothers of children with albinism face many challenges globally and society at large lacks knowledge about albinism. Some participants' experiences did not differ from the existing body of knowledge on albinism. The only difference is that studies in other African countries involved the general population while this study targeted mothers who have children with albinism.

The broad recommendations stemming from this study have implications for health science and general educational institutions, nurses and midwives especially those working with mothers and children, policy makers in the Ministry of Health in Malawi, the Malawian society, social media platforms and for further research in the field.

### **5.7.1 Recommendations for health science educational institutions**

Nursing, midwifery and medical/health science curricula and training workshops should include principles of genetic counselling and in Malawian health science institutions specifically albinism. Competence certificates should be issued.

## RATIONALE

Knowledge and understanding of albinism will help health science practitioners and specifically nurses and midwives to assist mothers in labour wards who give birth to babies with albinism to accept and deal competently with the situation. Nurses in other relevant hospital settings such as dermatology clinics who have this knowledge will be in a position to provide mothers of children who have albinism and adults living with albinism with evidence-based research on the use of sun protection skin products. Nurses should also have the knowledge to demystify and destigmatise the condition of albinism for sufferers. This will empower mothers of children with albinism to deal with community fears, superstitions and lack of knowledge.

### **5.7.2 Recommendations for other education institutions**

The study has revealed that the stigma surrounding children with albinism is also present in primary and high schools. Many children refuse to go to school for fear of being called names and being isolated by friends.

Albinism should be included in curricula for school teachers and in primary and secondary school curricula in Malawi.

## RATIONALE

Orientating children in primary and high schools will help them to understand that children with albinism are just like themselves and myths can be demystified to eliminate discrimination with its tragic sequelae.

### **5.7.3 Recommendations for health care clinical areas**

The study findings showed that most mothers of children with albinism did not know the cause of albinism despite some of them having had more than one child with albinism delivered at a hospital. Malawian midwives in maternity wards in district health centres should receive basic training in genetics to enable them to explain the genetic aetiology of albinism to mothers who deliver babies with albinism, to nursing colleagues and to local communities. In addition to midwives, all qualified nurses in maternity departments, antenatal wards and clinics for children under-5 years old should have knowledge of the principles of genetic counselling.

Mothers who give birth to children with albinism together with their families should receive counselling before they are discharged from hospital. Health talks about genetic conditions including albinism should be given to antenatal mothers. Health talks about the causes of albinism and

measures to be taken to protect the skin and the need for eye tests should be given in clinical settings attended by people with albinism when they collect free protective sun cream.

Findings from this study should inform child nursing and midwifery practice for more effective nursing interventions when dealing with mothers of children who have albinism. Effective nursing and midwifery interventions should include “reflection on practice” (reflection-on-action) (Schon, 1983:26) and “reflection in practice” (reflection-in-action) (Schon, 1983:68). In addition, effective interventions include good communication skills and knowledge translation to empower mothers of children who have albinism with knowledge and understanding to cope with such a situation. At a broader level, the findings should create awareness amongst other health practitioners and the local community about the facts relating to albinism and result in a safer society.

RATIONALE: Counselling will assist mothers who give birth to babies with albinism and family members to understand the cause of the condition of their baby and to accept the babies as they are and this should empower them to cope. Understanding the cause of the condition will save families from divorce which occurs due to misconceptions about albinism. Understanding the cause of albinism will help families to plan their pregnancies and to avoid marriages between closely related family members which contribute to the birth of children with albinism if parents are carriers of the gene.

#### **5.7.4 Recommendations for Policy Makers in the Ministry of Health at regional level in Malawi**

The Government of Malawi through the Ministry of Health should formulate a policy to protect people with albinism and facilitate effective implementation thereof. Those found guilty of harming persons who have albinism should be prosecuted and convicted.

Hospitals should have adequate financial and human resources to employ nurses and midwives in labour wards and dermatology clinics who are competent in genetic counselling and who have specific knowledge about albinism.

Protective sun creams should be free and distributed in sufficient quantities to persons with albinism by all district and not only central hospitals. Funding organisations should be recruited to be involved in promoting awareness of the facts about albinism.

#### **RATIONALE**

People with albinism will not have to travel long distances to collect supplies of sun cream and this will reduce the cost of transport.

Policy reinforcement will help to stop the killings and abuse which currently exists.

If maternity labour wards are well covered with competent staff, nurses and midwives will have the time to give appropriate information to mothers who give birth to children with albinism and to their families, because sometimes they may fail to do so due to work overload.

### **5.7.5 Recommendations for society**

Community awareness of albinism should be done through community leaders assisted by health professionals to educate mothers, school teachers and traditional healers about the cause of albinism and the psychosocial effects of stigma. In Malawi there are many community health outreach programmes which can be also utilised for this purpose. People in the community should be empowered to report crimes and killings related to people with albinism to the relevant authorities

RATIONALE: Strong community leadership will help demystify the myths and misperceptions held by society surrounding albinism.

### **5.7.6 Recommendations for Social Media platforms**

The Malawi Broadcasting Corporation Radio was identified as the participants' main source of information regarding albinism, despite there being more radio stations and other media platforms in Malawi so health professionals and community leaders should involve all of these. Talk shows with phone-in options are recommended.

#### RATIONALE

People who cannot afford a radio should be provided with posters and information brochures using pictures to make the message clear for those who are illiterate.

### **5.7.7 Recommendations for further research**

For this study to be replicated, it is recommended that the study sample should include health professionals from dermatology clinics or community members. Further research questions are suggested:

1. What knowledge and understanding of the cause of albinism, the medical and psychological effects associated with the condition and skin protection measures should mothers of children living with albinism have?
2. How should this knowledge and understanding of mothers of children with albinism be measured?
3. What information on albinism should nursing curricula in Malawian nursing educational institutions contain?

4. What type of support is required from the Malawian Government, health professionals in labour wards and in clinical areas dealing with albinism and society and pharmaceutical companies to help mothers of children living with albinism understand the cause of albinism, medical and psychological effects associated with the condition and skin protection measures?

## **5.8 CONCLUSION**

A description of the experiences and perceptions of mothers of children living with albinism in Malawi in this study has revealed that these children are stigmatised and unsafe in their communities and that these mothers experienced this acutely even though they were overwhelmingly positive about accepting and loving their children and attempted to protect them from harm whatever the cost. Overall, the mothers' understanding of the condition was poor and they had not received sufficient information from healthcare practitioners. Being the first such reported Malawian study it has filled a gap in the existing knowledge in this field and provides a foundation for further research specific to people living with albinism in Malawi.

## REFERENCES

---

- Amnesty International. Southern Africa Regional office. (2018). End violence against people with albinism: Towards Effective criminal justice for people with albinism in Malawi. 97 Oxford Road, Saxonwold, Johannesburg.
- Alhojailan, M. I. (2012). Thematic analysis: A critical review of its process and evaluation. *West East Journal of Social Sciences*, 1(1), 39-47.
- Allawh, R. M., & Norton, S. A. (2014). White shadows in a dark land. *JAMA dermatology*, 150(12), 1335-1335.
- Association, W. M. (2013). World Medical Association Declaration of Helsinki: ethical principles for medical research involving human subjects. *JAMA*, 310(20), 2191.
- Baker, C., Lund, P., Nyathi, R., & Taylor, J. (2010). The myths surrounding people with albinism in South Africa and Zimbabwe. *Journal of African Cultural Studies*, 22(2), 169-181.
- Bos, A. E., Pryor, J. B., Reeder, G. D., & Stutterheim, S. E. (2013). Stigma: Advances in theory and research. *Basic and Applied Social Psychology*, 35(1), 1-9.
- Braathen, S. H., & Ingstad, B. (2006). Albinism in Malawi: knowledge and beliefs from an African setting. *Disability & Society*, 21(6), 599-611.
- Bradbury-Jones, C., Ogik, P., Betts, J., Taylor, J., & Lund, P. (2018). Beliefs about people with albinism in Uganda: A qualitative study using the Common-Sense Model. *PloS One*, 13(10), e0205774.
- Brocco, G. (2015). Labeling albinism: language and discourse surrounding people with albinism in Tanzania. *Disability & Society*, 30(8), 1143-1157. doi:10.1080/09687599.2015.1075869
- Chan, Z. C., Fung, Y.-l., & Chien, W.-t. (2013). Bracketing in phenomenology: Only undertaken in the data collection and analysis process. *The Qualitative Report*, 18(30), 1-9.
- Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The psychologist*, 26(2), 120-123.
- Colorafi, K. J., & Evans, B. (2016). Qualitative descriptive methods in health science research. *HERD: Health Environments Research & Design Journal*, 9(4), 16-25.
- Creswell, J. W. (2009). Research design: Qualitative, quantitative, and mixed methods research: Los Angeles: SAGE.
- Creswell, J. W., Hanson, W. E., Clark Plano, V. L., & Morales, A. (2007). Qualitative research designs: Selection and implementation. *The counseling psychologist*, 35(2), 236-264.
- Creswell, J. W., & Miller, D. L. (2000). Determining Validity in Qualitative Inquiry. *Theory Into Practice*, 39(3), 124-130. doi:10.1207/s15430421tip3903\_2
- Cruz-Inigo, A. E., Ladizinski, B., & Sethi, A. (2011). Albinism in Africa: stigma, slaughter and awareness campaigns. *Dermatologic Clinics*, 29(1), 79-87.
- Denzin, N. K., & Lincoln, Y. (2000). Qualitative research. *Thousand Oaks ua*, 413-427.
- Edward, K.-L., & Welch, T. (2011). The extension of Colaizzi's method of phenomenological enquiry. *Contemporary Nurse*, 39(2), 163-171.
- Fayoyin, A., & Ihebuzor, N. (2014). ADVOCACY FOR MINORITIES IN AFRICA: ISSUES AND LESSONS IN ADVANCING THE RIGHTS OF ALBINOS IN TANZANIA AND OSUS IN NIGERIA. *Asia Pacific Journal of Research Vol: 1 Issue XVII*.
- Franklin, A., Lund, P., Bradbury-Jones, C., & Taylor, J. (2018). Children with albinism in African regions: their rights to 'being' and 'doing'. *BMC International Health and Human Rights*, 18(1), 2.
- Gill, P., Stewart, K., Treasure, E., & Chadwick, B. (2008). Methods of data collection in qualitative research: interviews and focus groups. *British Dental Journal*, 204(6), 291-295.
- Government of Malawi National statistical Office. (2018). 2018 population and housing census: preliminary report, December 2018. Retrieved from: [http://www.nsomalawi.mw/index.php?option=com\\_content&view=article&id=226:2018-malawi-population-and-housing-census&catid=8:reports&Itemid](http://www.nsomalawi.mw/index.php?option=com_content&view=article&id=226:2018-malawi-population-and-housing-census&catid=8:reports&Itemid)

- Hong, E. S., Zeeb, H., & Repacholi, M. H. (2006). Albinism in Africa as a public health issue. *BMC Public Health*, 6(1), 212.
- Imafidon, E. (2017). Dealing with the other between the ethical and the moral: albinism on the African continent. *Theoretical Medicine and Bioethics*, 38(2), 163-177.
- Kimbassa, N. (2016). *Albinism: Biomedical Information, Sociology and Human Rights Approaches to Disability*.
- Kisanga, P., & Mbonile, M. J. (2017). impact of interventions of the Murder of People with albinism in lake Victoria a case of Shinyanga region. *Journal of the Geographical Association of Tanzania*, 37(1).
- Koch, T. (2006). Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, 53(1), 91-100.
- Lekalakala, P., Khammissa, R., Kramer, B., Ayo-Yusuf, O., Lemmer, J., & Feller, L. (2015). Oculocutaneous albinism and squamous cell carcinoma of the skin of the head and neck in sub-Saharan Africa. *Journal of Skin Cancer*, 2015.
- Lewis, S. (2015). Qualitative inquiry and research design: Choosing among five approaches. *Health promotion practice*, 16(4), 473-475.
- Lynch, P., Lund, P., & Massah, B. (2014). Identifying strategies to enhance the educational inclusion of visually impaired children with albinism in Malawi. *International Journal of Educational Development*, 39, 216-224. doi:10.1016/j.ijedudev.2014.07.002
- Machoko, C. G. (2013). Albinism: a life of ambiguity, a Zimbabwean experience. *African Identities*, 11(3), 318-333.
- Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: guided by information power. *Qualitative Health Research*, 26(13), 1753-1760.
- Masanjala, M. M., Mvena, Z.S.K., & Kayunze, K. A. . (2014). Awareness, attitudes and level of albinos' predicament in Sukumaland, Tanzania. *ABC journals*, 3(4), 382-395.
- Mswela, M. (2017). Violent attacks against persons with albinism in South Africa: A human rights perspective. *African Human Rights Law Journal*, 17(1), 114-133.
- O'Brien, B. C., Harris, I. B., Beckman, T. J., Reed, D. A., & Cook, D. A. (2014). Standards for reporting qualitative research: a synthesis of recommendations. *Academic Medicine*, 89(9), 1245-1251.
- Orb, A., Eisenhauer, L., & Wynaden, D. (2001). Ethics in qualitative research. *Journal of Nursing Scholarship*, 33(1), 93-96.
- Phatoli, R., Bila, N., & Ross, E. (2015). Being black in a white skin: Beliefs and stereotypes around albinism at a South African university. *African Journal of Disability*, 4(1). doi:10.4102/ajod.v4i1.106
- Pooe-Monyemore, M. B., Mavundla, T. R., & Christianson, A. L. (2012). The experience of people with oculocutaneous albinism. *Health SA Gesondheid (Online)*, 17(1), 1-8.
- Rudan, I., Boschi-Pinto, C., Biloglav, Z., Mulholland, K., & Campbell, H. (2008). Epidemiology and etiology of childhood pneumonia. *Bulletin of the World Health Organization*, 86(5), 408-416B.
- Ruggunan, S. (2012). The labour market for histopathologists in KwaZulu-Natal: Emerging issues. *Health SA Gesondheid (Online)*, 17(1), 1-8.
- Sandelowski, M. (2000). Focus on research methods-whatever happened to qualitative description? *Research in Nursing and Health*, 23(4), 334-340.
- Schwering, M. S., Kumar, N., Bohrmann, D., Msukwa, G., Kalua, K., Kayange, P., & Spitzer, M. (2015). Refractive errors, visual impairment, and the use of low-vision devices in albinism in Malawi. *Graefe's Archive for Clinical and Experimental Ophthalmology*, 253(4), 655-661.
- Seibert, D. C., & Darling, T. N. (2013). Physical, psychological and ethical issues in caring for individuals with genetic skin disease. *Journal of Nursing Scholarship*, 45(1), 89-95.
- Serrano de la Vega, E. M. (2015). African Loanwords in the History of English: A Diachronic Study Based on the OED.
- Shosha, G. A. (2012). Employment of Colaizzi's strategy in descriptive phenomenology: A reflection of a researcher. *European Scientific Journal*, ESJ, 8(27).

- Simon, M. K., & Goes, J. (2013). Assumption, limitations, delimitations, and scope of the study: Doctoral dissertation, Dissertation and scholarly Research: Recipes for success.
- Speziale, H.J.S., & Carpenter, D. R. (2007). *Qualitative research in nursing. Advancing the humanistic imperative*. 4<sup>th</sup> edition: Lippincott Williams & Wilkin
- Tandon, S. (2016). Know more about albinism. *International Journal of Multidisciplinary approach and studies*, 3(1), 2348-2537X.
- Thwala, S. I. K., Ntinda, K., & Hlanze, B. (2015). Lived Experiences of Parents' of Children with Disabilities in Swaziland. *Journal of Education and Training Studies*, 3(4).  
doi:10.11114/jets.v3i4.902
- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*, 19(6), 349-357.
- Trochim, W. M. (2006). Qualitative measures. *Research measures knowledge base*, 361, 2-16.
- Tsang, S., Royse, C. F., & Terkawi, A. S. (2017). Guidelines for developing, translating, and validating a questionnaire in perioperative and pain medicine. *Saudi Journal of Anaesthesia*, 11(Suppl 1), S80.
- Watson, D. P. (2012). The evolving understanding of recovery: what does the sociology of mental health have to offer? *Humanity & society*, 36(4), 290-308.
- Wright, C. Y., Norval, M., Summers, B., Davids, L., Coetzee, G., & Oriowo, M. O. (2012). The impact of solar ultraviolet radiation on human health in sub-Saharan Africa. *South African Journal of Science*, 108(11-12), 45-51.

## APPENDIX 1

---

Division of Nursing & Midwifery  
Department of Health & Rehabilitation Sciences  
Faculty of Health Sciences  
University of Cape Town  
South Africa  
e-mail: nlikumbo @ yahoo.com  
Cell No: 0743821430

The Hospital Director  
CC: Chief Nursing Officer,  
Queen Elizabeth Central Hospital,  
Private bag 396  
Chichiri  
Blantyre 3

### RE: PERMISSION TO CONDUCT RESEARCH

Dear Sir/Madam

My name is Naomi Likumbo and I am a student currently studying for a Masters' degree in Nursing Science at the University of Cape Town. I am in the process of conducting research for my degree and I am writing to ask for permission to conduct my study at the dermatology clinic in your Facility. The title of the research is "Experiences and Perceptions of Mothers of Children living with Albinism in Malawi: A Qualitative descriptive study".

The nature of my study requires me to do face to face interviews with mothers of children with Albinism aged from 0-18 years old. Audio recording will also take place just for accurate primary information. Participation is voluntary. I have attached a proposal of my study which has ethics approval from the University of Cape Town, Faculty of Health Sciences Human Research Ethics Committee (HREC 828/2017) and those who volunteer to participate will be invited to sign a consent form (attached). If permission is granted, I please request that a nurse working in the dermatology clinic be identified to assist me in identifying potential participants who meet the inclusion criteria and to facilitate a meeting with potential participants. I would be most grateful if the nurse is able to locate a private and quiet place at the clinic for the individual interviews that will take place during working hours at a time convenient for the staff of the clinic and participants and for a period of 30 to 45 minutes for each interview. It may be necessary to provide a separate location if participants prefer not to be interviewed in the presence of the child who will then be looked after by a relative or person of the mother's choice.

All information collected from the participants will be treated as confidential and no information about participants will be shared with anyone not involved in the research. To ensure anonymity, no names but codes will be used for each participant. For the interviews, participants may choose a pseudonym to maintain anonymity.

The nature of my study does not involve any physical harm but sometimes asking a person to talk about experiences that were frightening, humiliating and/or painful can cause or increase anxiety. To ensure that

referral procedures are in place in case of emotions, I request the services of your dermatology clinic department nurses or clinicians with counselling roles or any available counsellor who is willing to receive a referral should this be necessary. After the study, you will be provided with an executive summary of the study findings.

Your permission to conduct the study at your hospital and to approach potential participants with the assistance of a nurse will be greatly appreciated and I will be happy to answer any questions related to the study. My contact details are indicated in the address above.

My supervisor's details are: Associate Professor Una Kyriacos

E-mail: [una.kyriacos@uct.ac.za](mailto:una.kyriacos@uct.ac.za), Telephone: 27-21-4066410

My co-supervisor's details are: telephone: Dr Tania de Villiers

Email: [tania.devilliers@uct.ac.za](mailto:tania.devilliers@uct.ac.za) Tel: 021 406 6321

Should you have any concerns regarding the ethical conduct, or human rights and welfare of any of the participants in the study, please contact:

**HUMAN RESEARCH ETHICS COMMITTEE DETAILS:**

Faculty of Health Sciences

Human Research Ethics Committee

Room E52-24 Groote Schuur Hospital Old Main Building

OBSERVATORY

7925

Professor Marc Blockman (Chairman)

Telephone number: 27-21 406 6338

Yours sincerely,

Naomi Likumbo

## **APPENDIX 2: INFORMATION SHEET**

---

**Participant Code Number:** \_\_\_\_\_

**Title of study: Experiences and Perceptions of Mothers of children living with albinism: A Qualitative descriptive study**

### **INFORMATION SHEET (Flesch Kincaid = 9,4)**

#### ***Why is this study being done?***

Hello, my name is Naomi Likumbo and I am a student at the University of Cape Town in South Africa. I am interested in asking mothers of children living with albinism about their experiences, perceptions of these experiences and their understanding of albinism and I would like to invite you to participate in the project.

#### ***Does the study have ethics approval?***

Approval (HREC REF: 828/2017) has been obtained from the UCT Faculty of Health Sciences' Human Research Ethics Committee.

#### ***Why am I being asked to take part?***

You have been asked to take part because the nature of the study requires responses from people who have experience of what the study is about and you qualify to give first-hand information.

#### ***What will happen if you decide to take part in the study?***

Please note that if you choose to participate, you will be asked to sign a consent form or if you prefer to give me a thumb print you can do so as proof of agreement and should you wish to stop taking part in the study at any time, you can do so without any negative results.

#### ***What will happen during the interview?***

You will be asked to answer questions; notes will be taken and your voice will be recorded with a digital voice recorder to ensure accurate information.

#### ***How will the given information be protected?***

All the information collected from you will be kept in locked files on a computer. Instead of using your real name I have given you a code number at the top of this page so that information you give me cannot identify you and the recording will be destroyed after three years. After the tape-recorded interview, I will type our discussion and either meet you again or telephone you to check that my record of the interview is correct but to do this I have another sheet of paper with your name and code number. I am the only person who has this list.

#### ***How long will this interview last?***

It should take about 30-45minutes to finish the interview.

#### ***What are the risks and discomforts for me taking part in this interview?***

The nature of my study does not involve any physical harm or discomfort but asking a person to talk about experiences that were frightening, humiliating and painful can cause or increase anxiety. It may not only create distress during an interview but even afterwards. In case that happens, arrangements have been made for you to speak with a health professional who has had additional training as a counsellor.

***To whom do I speak (or contact) if I have any questions about the study?***

Please feel free to ask me questions during any part of the study. If you have any further questions regarding the study you may contact me, or my supervisor or the University of Cape Town Faculty of Health Sciences Human Research Ethics Committee for more information about your rights and welfare as a research participant at telephone number 27 21 4066338. Details are provided at the bottom of the page.

***What if I decide not to take part?***

Please note that it is your own choice whether to participate or not. There will be no negative results if you decide not to participate in the study or if you stop your participation.

***Are there any benefits to you for being in this study?***

There are no financial benefits for you but refreshments will be provided during the interview if you agree to participate. This study will not benefit you directly but the findings of the study may help to improve the understanding of health personnel of mothers' experiences who have children living with Albinism in Malawi.

***What will happen when the study is over?***

After putting together all the information, the researcher will keep in touch with you in whatever way suits you (phone calls or face to face meetings) to verify results of the findings.

After the study, you will be provided with a summary of the findings if you request this. The researcher's telephone number is at the bottom of the page.

***Who you can contact if you have questions:***

**Researcher: Naomi Likumbo.**

Division of Nursing and Midwifery  
Department of Health and Rehabilitation Sciences  
Faculty of Health Sciences  
University of Cape Town,  
South Africa  
Telephone Number: 0743821430                      e-mail: nlikumbo@yahoo.com

**Supervisor: Assoc/Prof Una Kyriacos (Ph.D., UCT)**

Division of Nursing & Midwifery  
Department of Health & Rehabilitation Sciences  
Faculty of Health Sciences  
University of Cape Town  
OBSERVATORY 7925  
Telephone Number: 27 21 406 6410                      e-mail: una.kyriacos@uct.ac.za

**Co-Supervisor: Dr Tania's de Villiers (Ph.D., UCT)**

Telephone number: 27 21 4066410                      e-mails: tania.devilliers@uct.ac.za

**HUMAN RESEARCH ETHICS COMMITTEE DETAILS:**

Faculty of Health Sciences  
Human Research Ethics Committee  
Room E52-24 Groote Schuur Hospital Old Main Building

OBSERVATORY 7925

Professor Marc Blockman (Chairman) Telephone number: 27-21 406 6338

e-mail: [marc.blockman@uct.ac.za](mailto:marc.blockman@uct.ac.za)

**APPENDIX: 3****CONSENT FORM (Flesch Kincaid 9.5)**

Research team: Naomi Likumbo Masters of nursing student, Supervisor: Associate Professor Una Kyriacos, Co-supervisor: Dr Tania De Villiers.

	<b>Initials</b>
1. I give my permission for the interview to be audio-recorded.	
2. I (the participant) confirm that I have read and understand the information sheet for the study “Experiences and Perceptions of mothers of children living with Albinism in Malawi” (dated 2018) and have had the opportunity to ask questions and have them answered to my satisfaction	
3. I understand that my participation in the study will not affect the treatment I receive at the hospital.	
4. I am aware that I can stop taking part from the study at any time without penalty.	
5. I am aware that all my details on this consent form and in the interview, process are confidential and I cannot be identified. Information offered by me is confidential and protected by using a code instead of my name.	
6. I am aware that there are no physical risks involved.	
6. I understand that emotional risk may arise during the interview process. If that happens, I understand that arrangements have been made for me to speak with a trained counsellor if I wish to.	
7. I understand that questions asked during the interview may lead to me or the interviewer asking further questions.	
8. I am aware that there are no financial benefits and that there may be no direct benefit to me for participating in this study but nurses and other health professionals can learn from my experiences, perceptions and understanding of persons living with albinism and their families.	
8. I consent to take part in the above study and have reached this decision without coercion or undue pressure.	

Print name of participant

Signature

Date

Print Name of a witness (needed)

Signature

Date

Print name of researcher

Signature

Date

This study is being conducted by the University of Cape Town.

When complete: original copy to be kept with transcript documents with a second copy for the researcher. Please offer a third copy to the participant for own records.

## APPENDIX 4: INTERVIEW GUIDE

---

Participant Code Number..... /or Pseudonym.....

Place: .....

### [Greeting/Introduction] -

Hello, my name is Naomi Likumbo .and I am doing a study towards a Master’s degree in Nursing at University of Cape Town. Thank you for agreeing to participate in the study and I see that you have brought your signed consent form with you. Do you have any questions about the study or the consent form before we start?

### NATURE OF THE STUDY

I am interested in the way you see Albinism and your understanding of this condition as a mother raising a child with albinism in Malawi.

By signing the consent form, you have agreed that I may conduct a face-to-face interview with you. Please understand that your participation is voluntary. The choice to participate is yours alone. If you choose not to participate this will not affect the treatment you or your child receive at the clinic. If you choose to participate, but wish to withdraw at any time, you are free to do so.

I hope that you are sitting comfortably. The interview will be audio tape-recorded to ensure accurate information taking and should take about 30-45 minutes of your time. Please answer the questions. We can stop the interview at any time you feel you need a break.

So, let’s start: The questions in this section are about your experiences of being a mother raising a child with albinism in Malawi and your reflections on these experiences.

#### **1. Experiences (E) and perceptions (P) of experiences**

- 1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?
- 1.1P *Can you tell me the reason for such a feeling?*
- 1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?
- 1.2P *[If yes] What do you think may be the reasons for their reactions?*
- 1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?
- 1.3P *[If yes] what do you think could be the reasons for them to react that way?*
- 1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?

- 1.4P *What do you think may be the reasons for this?*
- 1.5. E How do friends, family members and neighbours treat you and your child now?
- 1.5P *What do you think may be the reasons for this treatment?*
- 1.6E Can you share with me any other difficulties/problems you have faced in raising your child?
- 1.6. P *Can you tell me your thoughts about all what you went through?*

The questions in the last part of the questionnaire are about your understanding of albinism.

## **2. *Understanding***

- 2.1 What is your own understanding of the cause of albinism?
- 2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?
- 2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?
- 2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?
- 2.5 Can you share with me your understanding of the information you found from these sources?
- 2.6 Can you share with me how you responded to this information?

Thank you very much for your time. Do you have anything to add? We will keep in touch just to make sure that the summary of the information I have made is correct.

## APPENDIX 5 ETHICS APPROVAL LETTER FROM (UCT)



UNIVERSITY OF CAPE TOWN  
Faculty of Health Sciences  
Human Research Ethics Committee



Room E53-46 Old Main Building  
Groote Schuur Hospital  
Observatory 7925  
Telephone [021] 406 6492  
Email [sunayah.ardjien@uct.ac.za](mailto:sunayah.ardjien@uct.ac.za)  
Website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms)

08 May 2018

**HREC REF: 828/2017**

**A/Prof U Kyriacos**  
Division of Nursing & Midwifery  
Health & Rehab Sciences  
F56/27-OMB

Dear A/Prof Kyriacos

**PROJECT TITLE: EXPERIENCES AND PERCEPTIONS OF MOTHERS OF CHILDREN LIVING WITH ALBINISM IN MALAWI. A QUALITATIVE DESCRIPTIVE STUDY (Masters' candidate-Ms N Likumbo)**

Thank you for your response letter, addressing the issues raised by the Human Research Ethics Committee (HREC).

It is a pleasure to inform you that the HREC has **formally approved** the above-mentioned study.

**Approval is granted for one year until the 30 MAY 2019.**

Please submit a progress form, using the standardised Annual Report Form if the study continues beyond the approval period. Please submit a Standard Closure form if the study is completed within the approval period.

(Forms can be found on our website: [www.health.uct.ac.za/fhs/research/humanethics/forms](http://www.health.uct.ac.za/fhs/research/humanethics/forms))

***We acknowledge that the student: Ms N Likumbo will also be involved in this study.***

**Please quote the HREC REF in all your correspondence.**

Please note that the ongoing ethical conduct of the study remains the responsibility of the principal investigator.

Please note that for all studies approved by the HREC, the principal investigator **must** obtain appropriate institutional approval, where necessary, before the research may occur.

Yours sincerely

Signature Removed

**PROFESSOR M. BLOCKMAN**  
**CHAIRPERSON, FHS HUMAN RESEARCH ETHICS COMMITTEE**

Federal Wide Assurance Number: FWA00001637.  
Institutional Review Board (IRB) number: IRB00001938

HREC:828/2017

## APPENDIX 6 PERMISSION LETTER FROM (QUECH)

Telephone: (265) 01 874 333 / 677 333  
Facsimile: (265) 01 8769/8  
Email: [quech@quech.mw](mailto:quech@quech.mw)

All communications should be addressed to:  
The Hospital Director



In reply please quote No.

QUEENELIZABETHCENTRALHOSPITAL  
P.O. BOX 95  
BLANTYRE  
MALAWI

21<sup>st</sup> June, 2018

Naomi Likumbo  
Division of Nursing & Midwifery  
Department of Health & Rehabilitation Sciences  
Faculty of Health Sciences  
University of Cape Town  
SOUTH AFRICA

Dear Naomi,

**PERMISSION TO CONDUCT A RESEARCH STUDY AT QUEEN  
ELIZABETH CENTRAL HOSPITAL**

This is to inform you that permission has been granted to conduct a research study on "**Experiences and Perceptions of Mothers of Children living with Albinism in Malawi: A Qualitative descriptive study**".

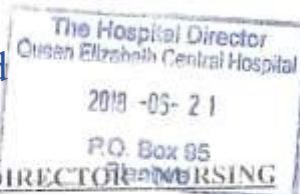
We will appreciate if a copy of your findings is shared with the hospital.

All the best in your studies.

Yours faithfully,

Signature Removed

L. Chewere  
**DEPUTY HOSPITAL DIRECTOR**



## APPENDIX 7 ETHICS APPROVAL LETTER FROM (NCSRH)



NATIONAL COMMISSION FOR SCIENCE & TECHNOLOGY

Lingadzi House  
Robert Mugabe Crescent  
P/Bag B303  
City Centre  
Lilongwe

Tel: +265 1 771 500  
+265 1 774 180  
+265 1 774 280  
Fax: +265 1 772 451  
Email: [director@ncst.mw](mailto:director@ncst.mw)  
Website: <http://www.ncst.mw>

### NATIONAL COMMITTEE ON RESEARCH IN THE SOCIAL SCIENCES AND HUMANITIES

Ref No: NCST/RTT/2/6

22<sup>nd</sup> June 2018

Ms Naomi Likumbo,

Anifield Village,

Forest Drive Extension,

Pinelands 7405,

South Africa.

Email: [nlikumbo@yahoo.com](mailto:nlikumbo@yahoo.com)

Dear Ms Likumbo,

#### **RESEARCH ETHICS AND REGULATORY APPROVAL AND PERMIT FOR PROTOCOL P.05/18/271: EXPERIENCES AND PERCEPTIONS OF MOTHERS OF CHILDREN LIVING WITH ALBINISM IN MALAWI: A QUALITATIVE DESCRIPTIVE STUDY**

Having satisfied all the relevant ethical and regulatory requirements, I am pleased to inform you that the above referred research protocol has officially been approved. You are now permitted to proceed with its implementation. Should there be any amendments to the approved protocol in the course of implementing it, you shall be required to seek approval of such amendments before implementation of the same.

This approval is valid for one year from the date of issuance of this approval. If the study goes beyond one year, an annual approval for continuation shall be required to be sought from the National Committee on Research Ethics in the Social Sciences and Humanities (NCRSH) in a format that is available at the Secretariat. Once the study is finalised, you are required to furnish the Committee and

#### **Committee Address:**

*Secretariat, National Committee on Research in the Social Sciences and Humanities, National Commission for Science and Technology, Lingadzi House, City Centre, P/Bag B303, Capital City, Lilongwe3, Malawi. Telephone Nos: +265 771 550/774 869; E-mail address: [ncrsh@ncst.mw](mailto:ncrsh@ncst.mw)*

the Commission with a final report of the study. The committee reserves the right to carry out compliance inspection of this approved protocol at any time as may be deemed by it. As such, you are expected to properly maintain all study documents including consent forms.

Wishing you a successful implementation of your study.

Yours Sincerely,

Signature Removed

Yalonda J. Mwanza  
NCRSH ADMINISTRATOR  
HEALTH, SOCIAL SCIENCES AND HUMANITIES DIVISION

For: CHAIRMAN OF NCRSH

**Committee Address:**  
*Secretariat, National Committee on Research in the Social Sciences and Humanities, National Commission for Science and Technology, Lingadzi House, City Centre, P/Bag B303, Capital City, Lilongwe3, Malawi. Telephone Nos: +265 771 550/774 869; E-mail address: ncrsh@ncst.mw*

## APPENDIX 8: Transcriptions by question

### Experiences (E) and perceptions (P) of experiences

**1.1E** *As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?*

- 1X1. "After my child was born the nurse told me that it was born with albinism and I accepted it without problems".
- 2X1. "I was so disappointed when I saw the child but my mother encouraged me that God cannot create something that is bad, I later accepted".
- 3X1. "When I saw my child, there was nothing that surprised me, I just accepted him".
- 4X1. "I just felt that it was a gift from God".
- 5X1. "I thank God that I just accepted my child at once".
- 6X1. "I felt pain but later on accepted that it is God's creation".
- 7X1. "I was happy because that was what God gave me".
- 8X1. "I accepted the child as a child without problems".
- 9X1. "Let me say, I was worried about where I was going to get sun cream, because I see children of this kind develop sores on their skin".
- 10X1. "It was so painful being my first child, eventually I accepted the child".

**1.1P** *Can you tell me the reason for such a feeling?*

- 1X2. Something in me just told me that I should accept him
- 2X2. "I was disappointed because I got pregnant and left school and only to give birth to "this kind of a child" but I also remembered that God cannot create something that is untrue".
- 3X2. I just felt that this child is born yes, I have to accept him just like any other child.
- 4X2. Because it is what God gave me.
- 5X2. "Something in me just told me to accept the child at once".
- 6x2. "It is what God gave me".
- 7X2. "I just thought that a child with albinism is just as any other child".
- 8X2. "I knew that he was a human being just like us".
- 9X2. "Because I have seen children of this type developing skin rashes".
- 10X2. "It was because of the gospel message that came on time, teaching about different gifts that people receive from God"

**1.2E** *Can you remember and describe the reaction of the nurses/midwives after your child was born?*

- 1X3. "I remember they were only surprised as the child was coming out, they thought it was something but after birth they did not look surprised".
- 2x3. "They just asked if the child was my first born and told me to take care of the child, get a supply of sun cream from the hospital to use for the rest of his life. They were also surprised because his skin was clear with no black spots nor rashes like most children born with albinism".
- 3X3. "Yes, I remember when he was born everyone was happy to see him, no one looked surprised".
- 4X3. "They accepted him and advised me to start collecting sunburn cream from the hospital".
- 5X3. "They did not say anything to me or show me my baby but went straight to my mother and asked what they should do with the baby without my knowledge".
- 6X3. "They looked surprised but did not tell me anything. I was only told how to care for my child at a certain age at the under-five clinic".
- 7X3. "I delivered through caesarean section and do not remember being told anything after waking up".
- 8X3. "The midwives were surprised and said "the child is a human being but different from other children".
- 9X3. "Aaaa!.. I cannot remember because I delivered through caesarean section, so I could not see".
- 10X3. "Yes, there were Doctors who told me that my child had no problems and that I must take care of the child".

**1.2P** *[If yes] What do you think may be the reasons for their reactions?*

- 1X4. "This was because "this thing" does not happen often, so it was strange to them".
- 2X4. "I think they were surprised because it could be their first time to deliver a child with albinism and also to see a child with albinism with no skin rashes or black spots".

- 3X4. "I think they did not want to disappoint me or, they were also interested with how the child was looking".
- 4X4. May be.... I can say God has a reason for everything he does in people's life.
- 5X4. "In my mind, I think they may be some people who ask midwives to kill their children when they are born with albinism; maybe that's why nurses were seeking permission on what to do with my child".
- 6X4. "Because of ignorance may be".
- 7X4. "I do not know why things happened that way"
- 8x4." They say a lot of things that I cannot say"
- 9X4. I did not see their reaction.
- 10X4. I just do not understand why things happen that way

**1.3E** *Can you remember and describe how your family members reacted after seeing your baby for the first time?*

- 1X5 "Most of my relatives were disappointed though some supported me because in our family I was the first one to give birth to a child of this kind".
- 2X5. "Some of them accepted him but some mocked me that how could I give birth to a child who stinks or smells like the sun he is going to bring calamity to us".
- 3X5. They accepted him without problems.
- 4X5. My relatives accepted him without any problems.
- 5X5. "In my family, there was no mistake but my husband's family did not accept the child, they said I had slept with someone with albinism to give birth to the child. My husband sent me home to my parents for six months till they got back to their senses".
- 6X5. "They accepted her but some were saying "look at the white person" we are going to sell her".
- 7X5." I remember my mother was shocked with the appearance of my child and was just showing everyone in the room. Saying "look at the appearance of this baby." but I told him that it was what God gave us. My sister-in-law laughed and accused me with another man with albinism".
- 8X5. "I think they just do not know what they are saying". "They say a lot of things that I cannot say".
- 9X5. "You know people talk, some were laughing that they cannot bear and keep a child with albinism"
- 10X5. "My family accepted my child and they still love him but my husband and his family did not accept the child and their relationship with the child is not good up to now".

**1.3P** *[If yes] what do you think could be the reasons for them to react that way?*

- 1X6. "I think because children with albinism are difficult to take care and they need to be protected from the sun because when they are exposed to sun their skin gets destroyed. It could also be because people of this kind are rarely found and maybe it was their first time to see a child of this kind"
- 2X6. "They did so because it was surprising and strange to them".
- 3X6. Aaa! I think maybe they did not want to disappoint me.
- 4X6. May be everyone just thought it was something from God.
- 5X6." I think they did so because my husband does not have albinism".
- 6X6." I have been despised that I and my children resemble a pig. I have another 18-year-old girl but she fears to date a normal man because she does not trust anyone and she struggles to get a job despite having a Malawi School Certificate of Education".
- 7X6. I think because it was her first time to see the child of that kind.
- 8X6." I get despised. People call her napwari, hair like a doll and some friends isolate her".
- 9X6" Lack of understanding and not knowing the truth about giving birth to a child with albinism".
- 10X6. "I think and heard that they think I had slept with another man with albinism because the father is black in complexion".

**1.4E** *As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?*

- 1X7. "As for me, I take care good of this child but his friends isolate him because of his appearance".
- 2X7. "I have been despised that I gave birth to a child that smells like sun. He is segregated by friends at school to the point that he refuses to go to school sometimes".
- 3X7. Aaa! Where I stay, everyone loves the child and everybody seem to be proud of him
- 4X7. A lot has been said but when you accept something you do not worry about what other people say.
- 5X7. "I love my child but other people spit out and some parents tell their children to touch their hair when they see her".
- 6X7." May be because they think a person with albinism is not a human being, does not live long, just disappear".

- 7X7. "People call my child "makobiri" meaning money. The say my child can be a source of money if I sell her. Some friends have suggested to me that hospital staff might have exchanged my child with the one I have".
- 8X7. "I think because they think an albinism is not a human being".
- 9X7. "Some neighbours are good; they help me to take care of the child and advise me not to leave the child alone. One of my neighbours has a child with albinism and she is the one who informed me that free sun cream is provided at Queen Elizabeth Central Hospital dermatology clinic".
- 10X7. "I do not sleep normally as you people do. I am scared especially at night thinking of what might happen when I am asleep. I have met a colleague at the clinic who was stabbed all over as he was trying to protect himself from people who wanted to cut his private part but failed because he fought with them and that... makes me more scared at night. I have also been accused of sleeping with another man and my marriage is affected; my husband asked me to choose between marriage and his own child of which I chose my child. My husband said plainly that he does not want this child".

**1.4P** *What do you think may be the reasons for this?*

- 1X8. "It could be possible that people are not happy because of his appearance".
- 2X8. "I do not know, but it could be that they have never seen a child with albinism".
- 3X8. I think they just do that to make me feel happy
- 4X8. "May be its because of their understanding, they do not see the importance of a person with albinism".
- 5X8. "I think and I have heard that they do so to prevent their children from turning into a child with albinism".
- 6X8. "Some relatives call her names such as: napweri, mzungu".
- 7X8. "They do that just to despise me and my child".
- 8X7. "I think because they think an albinism is not a human being".
- 9X8. "I think it is because they also know people with albinism are at risk of being missing or killed and also because this other neighbour understands the challenge of raising a child with albinism".
- 10X8. "May be lack of understanding that it was not my choice to give birth to a child like this".

**1.5 E** *How do friends, family members and neighbours treat you and your child now?*

- 1X9. "I take good care of her but some relatives and friends segregate the child sometimes".
- 2X9. "His friends mock him, isolate him and call him a white person who smell like the sun".
- 3X9. All friends and relatives show love to this child.
- 4X9. "I have no problem with my neighbours".
- 5X9. Some people talk like children with albinism are not important.
- 6X9. "They think a person with albinism is different from a normal person".
- 7X9. "I and the father, we both love her".
- 8X9. "Some people despise me that "how can I, black mother to give birth to a white child?"
- 9X9. They despise the child; calling names like Napweri, money and many bad things
- 10X9. "Most people love him, I should not lie but some of his friends mock him, calling him Napweri and refuse to play with him. Some of my friends have directly asked me as to why I did or do not kill my child and, I do not want to be anywhere close to them. Some neighbours have been discouraging me from going to the hospital for sun cream, they believe the hospital people have evil plans so they are attracting people with free sun cream but surprisingly this is the sixth year I have been coming and nothing has happened to my child".

**1.5P** *What do you think may be the reasons for this treatment?*

- 1X10. This happens because his appearance.
- 2X10. "It could be that it is strange to them".
- 3X10. The same reason of not wanting to disappoint me or it could be possible that they are interested with his appearance.
- 4X10. "They do not differentiate a child with albinism with a normal child".
- 5X10. "I think and I have heard that they do so to prevent their children from turning into a child with albinism".
- 6X10. "They think a person with albinism is different from a normal person".
- 7X10. "All is because we accepted her as a gift from God".
- 8X10 "I do not know".
- 9X10 "I think it is because they do not know what causes this to happen."
- 10X10. *May be that is what they know and believe.*

**1.6E Can you share with me any other difficulties/problems you have faced in raising your child?**

- 2X11." The challenges are: sometimes friends refuse to play with him, saying that he smells like sun, he is a white person, napwari. This make him refuse to go to school. Pregnant women also chase him, saying he will bring calamity "will make them deliver a child with albino".
- 3X11. "The main challenge I have gone through is losing my marriage. My ex- husband's relatives were talking a lot because my husband does not have albinism so I decided to get out of marriage and take care of my child".
- 4X11." There are times when some people have said to me as to why I did not kill the child when he was just born".
- 5X11." The six months separation from my husband was very painful to me and being accused of a thing I did not do (sleeping with another man with albinism) was a disgrace to me. I was also forced to put my child in a private school for safety reasons thou with difficulties in paying fees just to keep her on a nearer school to my area".
- 6X11. "People say that they stopped eating pork because of me; that I resemble a pig. I have money problems, sometimes I cannot afford to buy hat, long sleeved clothes and I also struggle to find transport money to go the clinic to get sun cream".
- 7X11. "In terms of sun burn cream, we are not given enough supply sometimes it does not last till the next appointment day, we spend a lot of transport coming to collect the cream, if they could consider giving us enough maybe it could be better".
- 8X 11. "She has vision problems and I cannot afford glasses but the teacher helped by putting her in front to read easily on the board".
- 9X11." Just a day before yesterday I was in the house and could not see him when I came out, when I asked his friends, I was told he was following another man who asked him to go with him, I run after them with my neighbour and the man suddenly disappeared, when I asked my child who the man was, he just said that the man told the child that he is" a bwana", a Chichewa term meaning "sir". This made me more scared than before. I also have been buying sun cream small tube at MK3,500 and large tube at MM7,000 from a colleague with albinism not knowing it is given for free at Queens Hospital. I have financial problems sometimes struggle to find transport money when going to collect sun cream".
- 10X11. "The child's father and his family do not support him financially; he only is supported by my parents". "He also does not see properly but I requested the teacher that maybe he should make his writings a little bigger".

**1.6. P Can you tell me your thoughts about all you went through?**

- 1X11. "Eish! I feel worried especially when I hear stories of people with albinism being abused and killed, I feel sorry for myself and scared".
- 1X12." I really feel scared but I put God first so that he should protect my child from people with evil thoughts who keep on following me without my knowledge".
- 2X12" I feel pain but I just ignore what people say because God cannot create a bad thing".
- 3X12. I said to myself "that I gave birth to this child, I will take care of her just as any other child.
- 4x12. It does not bother me because the child is mine.
- 5X12. "It is my prayer that this child grows into a responsible person to put to into shame those who despises her".
- 6X12. It pains me a lot.
- 7X12. "I am also scared of those people who call my child "money".
- 8X12." It pains me but I just pray for protection from God".
- 9X12. "I feel pain so much, considering that it is my first time to give birth"
- 10X12. "I always ask myself a question of what exactly the cause of this is"

**2. Understanding**

**2.1 What is your own understanding of the cause of albinism?**

- 1X13. "There is no difference between a person with albinism and any other person because when injured, we feel the same pain".
- 2X13." My understanding is that a child with albinism is just like any person".
- 3X13. "My understanding is that there are several causes of albinism but what I remember is that when genes are weak, a child fails to develop the top layer skin".
- 4X13." A child with albinism is just like any other child provided you follow advice on how to care for him"

- 5X13. "I just heard that its ge... or blood that resembles what....? Thus, what causes albinism but we are the same only that they lack the skin that protects them from the sun".
- 6X13. "A person with albinism is just like any human being".
- 7X13." I just heard that there is some paint in the abdomen. but I have forgotten its name which is found in men, and when it is in large amount. I don't know what happens but, its cancan cause albinism".
- 8X13. "A person with albinism is a human being just like anybody, we only differ in complexion".
- 9X13. "Let me just say people say it is caused by "mwanamphepo".
- 10X13. "I do not know or understand what exactly happens and I always ask myself that same question".

**2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you re regarding the condition of your child after he/she was born?**

- 1X14. "I was told that this child is different from any other child and needs to be protected from sun and they referred me to this hospital where I get a supply of sun burn cream".
- 2X14. "They just told me to take care of the child because he is just like any other human being".
- 3X14. "I was told that my child had weak genes and failed to develop the top layer of the skin but he is just as any other person. I was given an example that if a normal person has an open wound, a white skin appears first before blood comes out. That is what I grabbed".
- 4x14. "I was told that he should put-on long-sleeved clothes, sun hat and I should apply sun burn cream from the hospital".
- 5X14. "I was told nothing by the nurses, doctors after my child was born"
- 6X14. "I was told nothing at the hospital regarding albinism after giving birth".
- 7X14." I was told nothing by the medical people, they just sent me to cotton weaving company where I got information on how to care for my child".
- 8X14." I was told not to worry and not do anything to the child because she is a human being. Because some people think of killing a child just because he/she is born with albinism. I was advised to use sun cream and to protect his skin".
- 9X14. "I was not told anything when my child was born but I am not sure if my mother was told anything when she first came to the clinic to collect sun cream because I was sick and she came on my behalf".
- 10X14. "Like I said earlier on, I was just told that the child is normal; there is any problem with him".

**2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?**

- 1X15. "I can tell him that he is different from other children because that is how God created him, I cannot say much because at the hospital, I was not told why I gave birth to this kind of a child.
- 2X15. "He keeps on asking me why he looks different from me and I tell him that he is "mzungu", a term referring to a "white person" and is good looking than me".
- 3X15. "He once asked me that question but because he is a child, I just told him that" ndiwe mzungu kapena mwenye" (you are a white person or an Indian) and he believes because he finds his skin similar to those people".
- 4X15 I can tell him that it is how God created him.
- 5X15. I just tell her that we only differ in complexion but we are the same.
- 7X15. "I always tell my child that thus how God created her".
- 8X15. "I can tell him that he is the same as every human being".
- 9X15. "I just tell him that is how you are, and those black in complexion also were born like that".
- 10X15." I always tell him that "we are the same; we both have arms and that your friends are just jealous of your appearance".

**2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?**

- 1X16. "I remember one day, I just heard that for a child to be born with Albinism, there is a small problem found in a woman or man but I did not hear properly because I got there when the programme was almost finished".
- 2X16. "I just heard from Malawi Broadcasting Radio that we should take care of our children; they should not be walking alone".
- 3X16." Epee... I have never heard anything from the radio or Television apart from the doctors or, if I heard then I might have forgotten".
- 4X16 Mhuuu. "I do not remember".
- 5X16. "It made me realise that they were disappearing because they were killed or sold".

- 6X16. "I heard from the Malawi broadcasting radio that people with albinism are human beings, they should not be isolated".
- 7X16." Sometimes our community leader calls for a meeting for all people with albinism to advise us that we should not walk at night nor open the door for anybody at night".
- 8X16. "I heard from the radio that people with albinism are also human beings, we should love and not isolate them".
- 9X16. "Yes, I do hear from the radio that we should not let our children move alone, because some people can kill them. I just heard from the radio a day before yesterday that a boy went missing on Independence Day (6/7/2018) and was found dead and the police are suspecting the step father but both parents are arrested. It is scary".
- 10X16." I heard from the radio about people cutting and selling private parts of people with albinism".

**2.5 Can you share with me your understanding of the information you found from these sources?**

- 1X17. "My understanding is that, this child is the same as any other child and deserve love and care from me and his father".
- 2X17. "I understood well and I always follow my child when he is playing, it's like I am also playing to ensure his safety but the child is also affected because sometimes he refuses to go to school for fear of being killed".
- 3X17" Eeee... I have never heard anything from the radio or Television apart from the doctors or, if I heard then I might have forgotten".
- 4X17. Nothing to share.
- 5X17. "It made me realise that they were disappearing because they were killed or sold".
- 6X17." I understood the message and I always take care of myself and my child".
- 7X17. "I make use of this information and do not allow my child to go far from my house".
- 8X17. "I accepted it and got encouraged with the information".
- 9X17." I believed the story and I always hold my child by the hand when going anywhere: church, school or market".
- 10X17." I believed the story because it was from the radio".

**2.6 Can you share with me how you responded to this information?**

- 1X18. I accepted the advice because after three weeks I reported to the hospital for the supply of sun cream and I always protect him from sun.
- 2X18" I accepted it and am used to following my child wherever he is playing to ensure his safety".
- 3X18. I accepted everything I heard from the medical people.
- 4X18. "I only remember the advice given at the hospital and I accepted it".
- 5X18. "I live in fear; I do not know what I can do to protect my child".
- 6X18. "I accepted the information and I am always careful in whatever I do for fear of being killed".
- 9X16. "I realised that I cannot even trust my neighbours because they can turn against my child anytime".
- 10X18." I am so scared but I keep on Praying with my mother for protection and we encourage each other".

## APPENDIX 9 Individual Participants' Transcripts

---

### Transcript 1 Code number:01X Pseudonym: Chair

1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after birth?

1X1. "After my child was born the nurse told me that it was born with albinism and I accepted it without problems".

. 1.1P *Can you tell me the reason for such a feeling?*

1X2. Something in me just told me that I should accept him.

. 1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?

1X3. "I remember they were only surprised as the child was coming out, they thought it was something but after birth they did not look surprised".

.1.2P [If yes] *What do you think may be the reasons for their reactions?*

1X4. "This was because "this thing" does not happen often, so it was strange to them".

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

1X5. "Most of my relatives were disappointed though some supported me because in our family I was the first one to give birth to a child of this kind".

1.2P [If yes] *What do you think may be the reasons for their reactions?*

1X6. "I think because children with albinism are difficult to take care and they need to be protected from the sun because when they are exposed to sun their skin gets destroyed. It could also be because people of this kind are rarely found and maybe it was their first time to see a child of this kind"

.1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?

1X7. "As for me, I take care good of this child but his friends isolate him because of his appearance"

1.4P *What do you think may be the reasons for this?*

1X8. "It could be possible that people are not happy because of his appearance".

1.5. E How do friends, family members and neighbours treat you and your child now?

1X9. "I take good care of her but some relatives and friends segregate the child sometimes"

1.5P *What do you think may be the reasons for this treatment?*

1X10. This happens because his appearance.

1.6. P *Can you tell me your thoughts about all what you went through?*

1X11. "Eish! I feel worried especially when I hear stories of people with albinism being abused and killed, I feel sorry for myself and scared".

1X12." I really feel scared but I put God first so that he should protect my child from people with evil thoughts who keep on following me without my knowledge".

### UNDERSTANDING

2.1 What is your own understanding of the cause of albinism?

1X13. "There is no difference between a person with albinism and any other person because when injured, we feel the same pain".

2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?

- 1X14. "I was told that this child is different from any other child and needs to be protected from sun and they referred me to this hospital where I get a supply of sun burn cream".
- 2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?
- 1X15. "I can tell him that he is different from other children because that is how God created him, I cannot say much because at the hospital, I was not told why I gave birth to this kind of a child.
- 2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?
- 1X16. "I remember one day, I just heard that for a child to be born with Albinism, there is a small problem found in a woman or man but I did not hear properly because I got there when the programme was almost finished".
- 2.5 Can you share with me your understanding of the information you found from these sources?
- 1X17. "My understanding is that, this child is the same as any other child and deserve love and care from me and his father".
- 2.6 Can you share with me how you responded to this information?
- 1X18. I accepted the advice because after three weeks I reported to the hospital for the supply of sun cream and I always protect him from sun.

**Transcript 2. Code number: 02X pseudonym: (Martha)**

- 1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?
- 2X1. "I was so disappointed when I saw the child but my mother encouraged me that God cannot create something that is bad, I later accepted".
- 1.1P *Can you tell me the reason for such a feeling?*
- 2X2. "I was disappointed because I got pregnant and left school and only to give birth to "this kind of a child" but I also remembered that God cannot create something that is untrue".
- 1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?
- 2x3." They just asked if the child was my first born and told me to take care of the child, get a supply of sun cream from the hospital to use for the rest of his life. They were also surprised because his skin was clear with no black spots nor rashes like most children born with albinism".
- 1.2P [If yes] *What do you think may be the reasons for their reactions?*
- 2X4. "I think they were surprised because it could be their first time to deliver a child with albinism and also to see a child with albinism with no skin rashes or black spots".
- 1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?
- 2X5. "Some of them accepted him but some mocked me that how could I give birth to a child who stinks or smells like the sun he is going to bring calamity to us".
- 1.3P [If yes] *what do you think could be the reasons for them to react that way?*
- 2X6. "They did so because it was surprising and strange to them".
- 1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?
- 2X7. "I have been despised that I gave birth to a child that smells like sun. He is segregated by friends at school to the point that he refuses to go to school sometimes".
- 1.4P *What do you think may be the reasons for this?*
- 2X 8. "I do not know, but it could be that they have never seen a child with albinism".
- 1.5. E How do friends, family members and neighbours treat you and your child no

2X9. "His friends mock him, isolate him and call him a white person who smell like the sun".

1.5P *What do you think may be the reasons for this treatment?*

2X10. "It could be that it is strange to them".

1.6E Can you share with me any other difficulties/problems you have faced in raising your child?

2X11." The challenges are: sometimes friends refuse to play with him, saying that he smells like sun, he is a white person, napwari. This makes him refuse to go to school. Pregnant women also chase him, saying he will bring calamity "will make them deliver a child with albino".

1.6.P *Can you tell me your thoughts about all what you went through?*

2X12" I feel pain but I just ignore what people say because God cannot create a bad thing".

Understanding

2.1 What is your own understanding of the cause of albinism?

2X13." My understanding is that a child with albinism is just like any person".

2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?

2X14. "They just told me to take care of the child because he is just like any other human being".

2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?

2X15. "He keeps on asking me why he looks different from me and I tell him that he is "mzungu", a term referring to a "white person" and is good looking than me".

2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?

2X16. "I just heard from Malawi Broadcasting Radio that we should take care of our children, they should not be walking alone".

2.5 Can you share with me your understanding of the information you found from these sources?

2X17. "I understood well and I always follow my child when he is playing, it's like I am also playing to ensure his safety, but the child it also affected the child because sometimes they refuse going to school for fear of being killed".

2.6 Can you share with me how you responded to this information?

2X18" I accepted it and am used to following my child wherever he is playing to ensure his safety".

**Transcript 3 code number: 03X. (Pseudonym): Ida**

1.1E as a mother, can you share with me how you felt after seeing your baby for the first time after the birth?

3X1. "When I saw my child, there was nothing that surprised me, I just accepted him".

1.1P *Can you tell me the reason for such a feeling?*

3X2. I just felt that this child is born yes, I have to accept him just like any other child.

1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?

3X3. "Yes, I remember when he was born everyone was happy to see him, no one looked surprised".

1.2P [If yes] *What do you think may be the reasons for their reactions?*

3X4. "I think they did not want to disappoint me or, they were also interested with how the child was looking".

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

3X5. They accepted him without problems.

- 1.3P [If yes] *what do you think could be the reasons for them to react that way?*
- 3X6. Aaa! I think maybe they did not want to disappoint me.
- 1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?
- 3X7. Aaa! Where I stay, everyone loves the child and everybody seem to be proud of him
- 1.4P *What do you think may be the reasons for this?*
- 3X8. I think they just do that to make me feel happy.
- 1.5. E How do friends, family members and neighbours treat you and your child now?
- 3X9. All friends and relatives show love to this child.
- 1.5P *What do you think may be the reasons for this treatment?*
- 3X10. The same reason of not wanting to disappoint me or it could be possible that they are interested with his appearance.
- 1.6E Can you share with me any other difficulties/problems you have faced in raising your child?
- 3X11. "The main challenge I have gone through is losing my marriage. My ex- husband's relatives were talking a lot because my husband does not have albinism so I decided to get out of marriage and take care of my child"
- 1.6. P *Can you tell me your thoughts about all what you went through?*
- 3X12. I said to myself "that I gave birth to this child, I will take care of her just as any other child.

#### Understanding

- 2.1 What is your own understanding of the cause of albinism?
- 3X13. "My understanding is that there are several causes of albinism but what I remember is that when genes are weak, a child fails to develop the top layer skin".
- 2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?
- 3X14. "I was told that my child had weak genes and failed to develop the top layer of the skin but he is just as any other person. I was given an example that if a normal person has an open wound, a white skin appears first before blood comes out. That is what I grabbed".
- 2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?
- 3X15. "He once asked me that question but because he is a child, I just told him that" ndiwe mzungu kapena mwenye" (you are a white person or an Indian) and he believes because he finds his skin similar to those people".
- 2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?
- 3X16." Eeee... I have never heard anything from the radio or Television apart from the doctors or, if I heard then I might have forgotten".
- 2.5 Can you share with me your understanding of the information you found from these sources?
- 3X17. "I should just say I have never heard anything".
- 2.6 Can you share with me how you responded to this information?
- 3X18. I accepted everything I heard from the medical people.

#### **Transcript 4: code: 04X pseudonym: Agi**

As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?

- 4X1. "I just felt that it was a gift from God"

1.1P *Can you tell me the reason for such a feeling?*

4X2. Because it is what God gave me.

1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?

4X3. "They accepted him and advised me to start collecting sunburn cream from the hospital".

1.2P [If yes] *What do you think may be the reasons for their reactions?*

4X4. May be.... I can say God has a reason for everything he does in people's life.

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

4X5. My relatives accepted him without any problems.

1.3P [If yes] *what do you think could be the reasons for them to react that way?*

4X6. May be everyone just thought it was something from God.

1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?

4X7. A lot has been said but when you accept something you do not worry about what other people say.

1.4P *What do you think may be the reasons for this?*

4X8. "May be its because of their understanding, they do not see the importance of a person with albinism".

1.5. E How do friends, family members and neighbours treat you and your child now?

4X9. "I have no problem with my neighbours".

1.5P *What do you think may be the reasons for this treatment?*

4X10. "They do not differentiate a child with albinism with a normal child".

1.6E Can you share with me any other difficulties/problems you have faced in raising your child?

4X11. "There are times when some people have said to me as to why I did not kill the child when he was just born".

1.6. P *Can you tell me your thoughts about all what you went through?*

4x12. It does not bother me because the child is mine.

Understanding

2.1 What is your own understanding of the cause of albinism?

4X13. "A child with albinism is just like any other child provided you follow advice on how to care for him"

2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?

4x14. "I was told that he should put-on long-sleeved clothes, sun hat and I should apply sun burn cream from the hospital".

2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?

4X15 I can tell him that it is how God created him.

2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?

4X16 Mhuuu. "I do not remember".

2.5 Can you share with me your understanding of the information you found from these sources?

4X17. None.

2.6 Can you share with me how you responded to this information?

4X18. "I only remember the advice given at the hospital and I accepted it".

**Transcript: Code: 05X Pseudonym: Catherine Banda**

1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?

5X1. "I thank God that I just accepted my child at once".

1.1P *Can you tell me the reason for such a feeling?*

5X2. "Something in me just told me to accept the child at once".

1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?

5X3. "They did not say anything to me or show me my baby but went straight to my mother and asked what they should do with the baby without my knowledge".

1.2P [If yes] *What do you think may be the reasons for their reactions?*

5X4. "In my mind, I think they may be some people who ask midwives to kill their children when they are born with albinism; maybe that's why nurses were seeking permission on what to do with my child".

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

5X5. "In my family, there was no mistake but my husband's family did not accept the child, they said I had slept with someone with albinism to give birth to the child. My husband sent me home to my parents for six months till they got back to their senses".

1.3P [If yes] *what do you think could be the reasons for them to react that way?*

5X6." I think they did so because my husband does not have albinism".

1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?

5X7. "I love my child but other people spit out and some parents tell their children to touch their hair when they see her".

1.4P *What do you think may be the reasons for this?*

5X8. "I think and I have heard that they do so to prevent their children from turning into a child with albinism".

1.5. E How do friends, family members and neighbours treat you and your child now?

5X9 Some people talk like children with albinism are not important.

1.5P *What do you think may be the reasons for this treatment?*

5X10 "I think and I have heard that they do so to prevent their children from turning into a child with albinism".

1.6E Can you share with me any other difficulties/problems you have faced in raising your child?

5X11." The six months separation from my husband was very painful to me and being accused of a thing I did not do (sleeping with another man with albinism) was a disgrace to me. I was also forced to put my child in a private school for safety reasons thou having difficulties in paying fees just to keep her on a nearer school to my area".

1.6. P *Can you tell me your thoughts about all what you went through?*

5X12. "It is my prayer that this child grows into a responsible person to put to into shame those who despise her".

#### Understanding

2.1 What is your own understanding of the cause of albinism?

5X13. "I just heard that its ge... or blood that resembles what...? Thus, what causes albinism but we are the same only that they lack the skin that protects them from the sun".

Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?

5X14. "I was told nothing by the nurses, doctors after my child was born".

2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?

5X15. I just tell her that we only differ in complexion but we are the same.

2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?

5X16." I have once heard from friends that people with albinism just disappear, they do not die. I have also heard from the radio that other people think people with albinism are a source of wealth as such they kill them or sell them. I heard from friends that someone sold her own sister's daughter. I have also heard that some people come like thieves at night but just to steal a child with albinism and nothing else".

2.5 Can you share with me your understanding of the information you found from these sources?

5X17. "It made me realise that they were disappearing because they were killed or sold".

2.6 Can you share with me how you responded to this information?

5X18. "I live in fear; I do not know what I can do to protect my child".

### Transcript 06X Doreen

1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?

6X1. "I felt pain but later on accepted that it is God's creation".

1.1P Can you tell me the reason for such a feeling?

6x2. "It is what God gave me".

1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?

6X3. "They looked surprised but did not tell me anything. I was only told how to care for my child at a certain age at the under-five clinic".

1.2P [If yes] What do you think may be the reasons for their reactions?

6X4. "Because of ignorance may be".

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

6X5. "They accepted her but some were saying "look at the white person" we are going to sell her".

1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?

6X6." I have been despised that I and my children resemble a pig. I have another 18-year-old girl but she fears to date a normal man because she does not trust anyone and she struggles to get a job despite having a Malawi School Certificate of Education".

1.4P What do you think may be the reasons for this?

6X7." May be because they think a person with albinism is not a human being, does not live long, just disappear".

1.5. E How do friends, family members and neighbours treat you and your child now?

6X8. "Some relatives call her names such as: napweri, mzungu".

1.5P What do you think may be the reasons for this treatment?

6X9. "They think a person with albinism is different from a normal person".

1.6E Can you share with me any other difficulties/problems you have faced in raising your child?

6X10. "People say that they stopped eating pork because of me; that I resemble a pig. I have money problems, sometimes I cannot afford to buy hat, long sleeved clothes and I also struggle to find transport money to go the clinic to get sun cream".

1.6. P Can you tell me your thoughts about all what you went through?

6X11. It pains me a lot.

Understanding

- 2.1 What is your own understanding of the cause of albinism?
- 6X12. "A person with albinism is just like any human being".
- 2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?
- 6X13. "I was told nothing at the hospital regarding albinism after giving birth".
- 2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?
- 6X14. "I tell my child that thus how God created you".
- 2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?
- 6X15. "I heard from the Malawi broadcasting radio that people with albinism are human beings, they should not be isolated".
- 2.5 Can you share with me your understanding of the information you found from these sources?
- 6X16. "I understood the message and I always take care of myself and my child".
- 2.6 Can you share with me how you responded to this information?
- 6X17. "I accepted the information and I am always careful in whatever I do for fear of being killed".

**Transcript 7 Code number: 07X pseudonym: Chrissy.**

5/07/2016.

1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?

7X1. "I was happy because that was what God gave me".

1.1P Can you tell me the reason for such a feeling?

7X2. "I just thought that a child with albinism is just as any other child".

1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born

7X3. "I delivered through caesarean section and do not remember being told anything after waking up".

1.[If yes] What do you think may be the reasons for their reactions?

7X4. "I do not know why things happened that way"

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

7X5. "I remember my mother was shocked with the appearance of my child and was just showing everyone in the room. Saying "look at the appearance of this baby." but I told him that it was what God gave us. My sister-in-law laughed and accused me with another man with albinism".

1.3P [If yes] what do you think could be the reasons for them to react that way?

7X6. I think because it was her first time to see the child of that kind.

1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?

7X7. "People call my child "makobiri" meaning money. The say my child can be a source of money if I sell her. Some friends have suggested to me that hospital staff might have exchanged my child with the one I have".

1.4P What do you think may be the reasons for this?

7X8. "They do that just to despise me and my child".

1.5. E How do friends, family members and neighbours treat you and your child now?

7X9. "I and the father, we both love her".

1.5P *What do you think may be the reasons for this treatment?*

7X10. "All is because we accepted her as a gift from God".

1.6E Can you share with me any other difficulties/problems you have faced in raising your child?

7X11. "In terms of sun burn cream, we are not given enough supply sometimes it does not last till the next appointment day, we spend a lot of transport coming to collect the cream, if they could consider giving us enough maybe it could be better".

1.6. P *Can you tell me your thoughts about all what you went through?*

7X12. "I am also scared of those people who call my child "money".

Understanding

2.1 What is your own understanding of the cause of albinism?

7X13." I just heard that there is some paint in the abdomen. but I have forgotten its name which is found in men, and when it is in large amount. I don't know what happens but, it can cause albinism".

2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?

7X14." I was told nothing by the medical people, they just sent me to cotton weaving company where I got information on how to care for my child".

2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?

7X15. "I always tell my child that thus how God created her".

2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?

7X16." Sometimes our community leader calls for a meeting for all people with albinism to advise us that we should not walk at night nor open the door for anybody at night".

"I also heard on the Malawi broadcasting radio yesterday that the chairperson of our association was found dead and buried but the police is still investigating".

2.5 Can you share with me your understanding of the information you found from these sources?

7X17. "I make use of this information and do not allow my child to go far from my house".

2.6 Can you share with me how you responded to this information?

**Transcript 8 Code number: 08X: pseudonym: Lines. Lines.**

1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?

8X1" I accepted the child as a child without problems".

1.1P *Can you tell me the reason for such a feeling?*

8X2. "I knew that he was a human being just like us".

1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?

8X3. "The midwives were surprised and said "the child is a human being but different from other children".

1.2P *What do you think may be the reasons for their reactions?*

8X4 Maybe it was their first time to see that kind of a baby.

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

8X5." They say a lot of things that I cannot say".

- 1.3P [If yes] *what do you think could be the reasons for them to react that way?*
- 8X6. "I think they just do not know what they are saying".
- 1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?
- 8X7." I get despised. People call her napweri, hair like a doll and some friends isolate her".
- 1.4P *What do you think may be the reasons for this?*
- 8X8. "I think because they think an albinism is not a human being".
- 1.5. E How do friends, family members and neighbours treat you and your child now?
- 8X9. "Some people despise me that "how can I, black mother to give birth to a white child?"
- 1.5P *What do you think may be the reasons for this treatment?*
- 8X10 "I do not know".
- 1.6E Can you share with me any other difficulties/problems you have faced in raising your child?
- 8X 11. "She has vision problems and I cannot afford glasses but the teacher helped by putting her in front to read easily on the board".
- 1.6. P *Can you tell me your thoughts about all what you went through?*
- 8X12." It pains me but I just pray for protection from God".

#### Understanding

- 2.1 What is your own understanding of the cause of albinism?
- 8X13. "A person with albinism is a human being just like anybody, we only differ in complexion".
- 2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?
- 8X14." I was told not to worry and not do anything to the child because she is a human being. Because some people think of killing a child just because he/she is born with albinism. I was advised to use sun cream and to protect his skin".
- 2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?
- 8X15. "I can tell him that he is the same as every human being".
- 2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?
- 8X16. "I heard from the radio that people with albinism are also human beings, we should love and not Isolate them".
- 2.5 Can you share with me your understanding of the information you found from these sources?
- 8X17. "I accepted it and got encouraged with the information".
- 2.6 Can you share with me how you responded to this information?
- 8X18 I was happy with the message.

#### Transcript 9. Code Number: 09X Pseudonym: Fatima

12/7/18

##### 2. *Experiences (E) and perceptions (P) of experiences*

- 1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?
- 9X1. "Let me say, I was worried about where I was going to get sun cream, because I see children of this kind develop sores on their skin".
- 1.1P *Can you tell me the reason for such a feeling?*

- 9X2.” *Because I have seen children of this type developing skin rashes”.*
- 1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?
- 9X3. *“Aaaa!.. I cannot remember because I delivered through caesarean section, so I could not see”.*
- 1.2P [If yes] *What do you think may be the reasons for their reactions?*
- 9X4. I did not see their reaction.
- 1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?
- 9X5. *“You know people talk, some were laughing that they cannot bear and keep a child with albinism”*
- 1.3P [If yes] *what do you think could be the reasons for them to react that way?*
- 9X6” *Lack of understanding and not knowing the truth about giving birth to a child with albinism”.*
- 1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?
- 9X7. *“Some neighbours are good; they help me to take care of the child and advise me not to leave the child alone. One of my neighbours has a child with albinism and she is the one who informed me that free sun cream is provided at Queen Elizabeth Central Hospital dermatology clinic”.*
- 1.4P *What do you think may be the reasons for this?*
- 9X8. *“I think it is because they also know people with albinism are at risk of being missing or killed and also because this other neighbour understands the challenge of raising a child with albinism”.*
- 1.6E Can you share with me any other difficulties/problems you have faced in raising your child?
- 9X9.” *Just a day before yesterday, I was in the house and could not see him when I came out, when I asked his friends, I was told he was following another man who asked him to go with him, I run after them with my neighbour and the man suddenly disappeared, when I asked my child who the man was, he just said that the man told the child that he is” a bwana”, a Chichewa term meaning “sir”. This made me more scared than before. I also have been buying sun cream small tube at MK3,500 and large tube at MM7,000 from a colleague with albinism not knowing it given for free at Queens Hospital. I have financial problems sometimes struggle to find transport money when going to collect sun cream”.*
- 1.6. P *Can you tell me your thoughts about all what you went through?*
- 9X10. *“I feel pain so much, considering that it is my first time to give birth”*

The questions in the last part of the questionnaire are about your understanding of albinism.

## 2. *Understanding*

- 2.1 What is your own understanding of the cause of albinism?
- 9X11. *“Let me just say people say it is caused by “mwanamphepo”.*
- 2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?
- 9X12. *“I was not told anything when my child was born but I am not sure if my mother was told anything when she first came to the clinic to collect sun cream because I was sick and she came on my behalf”.*
- 2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?
- 9X13. *“I just tell him that that is how you are, and those black in complexion also were born like that”.*
- 2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?
- 9X14. *“Yes, I do hear from the radio that we should not let our children move alone, because some people can kill them. I just heard from the radio a day before yesterday that a boy went missing on Independence Day (6/7/2018) and was found dead, and the police are suspecting the step father but both parents are arrested. It is scary”.*
- 2.5 Can you share with me your understanding of the information you found from these sources?

9X15. "I believed the story and I always hold my child by the hand when going anywhere: church, school or market".

2.6 Can you share with me how you responded to this information?

9X16. "I realised that I cannot even trust my neighbours because they can turn against my child anytime".

Thank you very much for your time. Do you have anything to add? We will keep in touch just to make sure that the summary of the information I have made is correct.

**Transcript: 10. Code Number: 10X Pseudonym: Fanny. 12/7/2018**

**1. Experiences (E) and perceptions (P) of experiences**

1.1E As a mother, can you share with me how you felt after seeing your baby for the first time after the birth?

10X1. "It was so painful being my first child, eventually I accepted the child".

1.1P Can you tell me the reason for such a feeling?

10X2. "It was because of the gospel message that came on time, teaching about different gifts that people receive from God"

1.2E Can you remember and describe the reaction of the nurses/midwives after your child was born?

10X3. "Yes, there were Doctors who told me that my child had no problems and that I must take care of the child"

1.2P [If yes] What do you think may be the reasons for their reactions?

10X4. I just do not understand why things happen that way.

1.3E Can you remember and describe how your family members reacted after seeing your baby for the first time?

10X5. "My family accepted my child and they still love him but my husband and his family did not accept the child and their relationship with the child is not good up to now".

1.3P [If yes] what do you think could be the reasons for them to react that way?

10X6. "I think and heard that they think I had slept with another man with albinism because the father is black in complexion".

1.4E As a mother, can you explain in your own words your experiences of raising a child with Albinism in your community?

10X7. "I do not sleep normally as you people do. I am scared especially at night thinking of what might happen when I am asleep. I have met a colleague at the clinic who was stabbed all over as he was trying to protect himself from people who wanted to cut his private part but failed because he fought with them and that... makes me more scared at night. I have also been accused of sleeping with another man and my marriage is affected; my husband asked me to choose between marriage and his own child of which I chose my child. My husband said plainly that he does not want this child".

1.4P What do you think may be the reasons for this?

10X8. "May be lack of understanding that it was not my choice to give birth to a child like this".

1.5. E How do friends, family members and neighbours treat you and your child now

10X9. "Most people love him, I should not lie but some of his friends mock him, calling him Napweri and refuse to play with him. Some of my friends have directly asked me as to why I did or do not kill my child and, I do not want to be anywhere close to them. Some neighbours have been discouraging me from going to the hospital for sun cream, they believe the hospital people have evil plans so they are attracting people with free sun cream but surprisingly this is the sixth year I have been coming and nothing has happened to my child".

1.5P What do you think may be the reasons for this treatment?

10X10. May be that is what they know and believe.

1.6E Can you share with me any other difficulties/problems you have faced in raising your child?

10X11. "The child's father and his family do not support him financially; he only is supported by my parents".  
"He also does not see properly but I requested the teacher that maybe he should make his writings a little bigger".

1.6. P *Can you tell me your thoughts about all what you went through?*

10X12. "I always ask myself a question of what exactly the cause of this is"

The questions in the last part of the questionnaire are about your understanding of albinism.

## 2. *Understanding*

2.1 What is your own understanding of the cause of albinism?

10X13. "I do not know or understand what exactly happens and I always ask myself that same question".

2.2 Can you explain to me what the medical professionals (Doctors, Nurses or Counsellors) told you regarding the condition of your child after he/she was born?

10X14. "Like I said earlier on, I was just told that the child is normal; there is no any problem with him".

2.3 If your child could ask you today the reasons for her white appearance and poor eyesight, what would your answer be?

10X15." I always tell him that "we are the same; we both have arms and that your friends are just jealous of your appearance".

2.4 Can you tell me where else you found information about Albinism (for example friends, radio, television, family or community leaders) and the type of information?

10X16." I heard from the radio about people cutting and selling private parts of people with albinism".

2.5 Can you share with me your understanding of the information you found from these sources?

10X17." I believed the story because it was from the radio".

2.6 Can you share with me how you responded to this information?

10X18." I am so scared but I keep on Praying with my mother for protection and we encourage each other".

Thank you very much for your time. Do you have anything to add? We will keep in touch just to make sure that the summary of the information I have made is correct.

## APPENDIX 10: Coded data

Significant statements	Transcript number	Page number	Line number codes
After my child was born the nurse told me that it was born with albinism and I accepted it without problems.	1	1	1X1
I remember they were only surprised as the child was coming out, they thought it was something but after birth they did not look surprised.	1	1	1X3
This was because “this thing” does not happen often, so it was strange to them.	1	1	1X4
Most of my relatives were disappointed though some supported me because in our family I was the first one to give birth to a child of this kind.	1	1	1X5
I think because children with albinism are difficult to take care of, they need to be protected from the sun because when they are exposed to sun their skin gets destroyed. It could also be because people of this kind are rarely found and maybe it was their first time to see a child of this kind	1	1	1X6
I take good care of this child but his friends isolate him because of his appearance. It could be possible that people are not happy because of his appearance. some relatives and friends segregate the child sometimes.	1	1	1X7 -1X9
Eish! I feel worried especially when I hear stories of people with albinism being abused, I feel sorry for myself and scared of evil people who keep on following me without my knowledge	1	2	1X11
I feel scared but I put God first so that he should protect my child from people with evil thoughts who keep on following me without my knowledge	1	2	1X12
There is no difference between a person with albinism and any other person because when injured, we feel the same pain.	1	2	1X13
I was told that this child is different from any other child and needs to be protected. because at the hospital, I was not told why I gave birth to this kind of a child	1	2	1X14
“I just heard that for a child to be born with Albinism, there is a small problem found in a woman or man but I did not hear properly because I got there when the programme was coming to an end”.	1	2	1X16
“My understanding is that, this child is the same as any other child and deserve love and care from me and his father”.	1	2	1X17
“I was so disappointed when I saw the child but my mother encouraged me that God cannot create something that is bad, I later accepted”.	2	3	2X1
“I was disappointed because I got pregnant and left school and only to give birth to this kind of a child”.	2	3	2X2
“They just asked if the child was my first born and told me to take care of the child, get a supply of sun cream from the hospital to use for the rest of his life. They were also surprised because his skin was clear with no black spots nor rashes like most children born with albinism”. “I think they were surprised because it could be their first time to see a child with albinism but also with no skin rashes or black spots”.	2	3	2X3 and 2X4
“Some of them accepted him but some mocked me that how could I give birth to a child who stinks or smells like the sun he is going to bring calamity to us”.	2	3	2X5
“They did so because it was surprising and strange to them”.	2	3	2X6
“I have been despised that I gave birth to a child that smells like sun. His friends mock him, isolate him and call him a white person who smell like the sun to a child that smells like sun. He is segregated by friends at school to the point that he refuses to go to school at times. When he meets pregnant women, they chase him away because they are afraid of giving birth to a child with albinism”.	2	3-4	2X7, 2X9,2X11

"I do not know, but it could be that they have never seen a child with albinism". "It could be that it is strange to them".	2	4	2X8 and 2X10
"I feel pain but I just ignore what people say because God cannot create a bad thing"	2	4	2X12
"My understanding is that a child with albinism is just like any person".	2	4	2X13
"They just told me to take care of the child because he is just like any other human being".	2	4	2X14
"He keeps on asking me why he looks different from me and I tell him that he is white person and is good looking than me".	2	4	2X15
"I just heard that we should take care of our children, they should not be walking alone. I always follow my child when he is playing, it's like I am also playing to ensure his safety".	2	4	2X16
"I understood well and I always follow my child when he is playing, it is like I am also playing to ensure his safety but the child it also affected the child because sometimes they refuse going to school for fear of being killed".	2	4	2X17
I accepted it and am used to following my child wherever he is playing to ensure his safety.	2	4	2X18
"When I saw my child, there was nothing that surprised me, I just accepted him"	3	5	3X1
"Yes, I remember when he was born everyone was happy to see him, no one looked surprised"	3	5	3X3
"I think they did not want to disappoint me or, they were also interested with how the child was looking"	3	5	3X4
"The main challenge I have gone through is losing my marriage. My ex- husband's relatives were talking a lot because my husband does not have albinism so I decided to get out of marriage and take care of my child".	3	6	3X11
"My understanding is that there are several causes of albinism but what I remember is that when genes are weak, a child fails to develop the top layer skin".	3	6	3X13
"I was told that my child had weak genes and failed to develop skin but he is just as any other person. I was given an example that if a normal person has an open wound, a white skin appears first before blood comes out. That is what I grabbed".	3	6	3X14
"He once asked me that question but because he is a child, I just told him that" ndiwe mzungu kapena mwenye" (you are a white person or an Indian) and he believed because he finds his skin similar to those people".	3	6	3X15
"Eeee... I have never heard anything from the radio or Television apart from the doctors or, if I heard then I might have forgotten".	3	6	3X16
"I should just say I have never heard anything".	3	6	3X17
"I should just say I have never heard anything".	4	7	4X1
"They accepted him and advised me to start collecting sunburn cream from the hospital".	4	7	4X3
"May be its because of their understanding, they do not see the importance of a person with albinism".	4	7	4X8
"I have no problem with my neighbours"	4	7	4X9
"They do not differentiate a child with albinism with a normal child".	4	7	4X10
"There are times when some people have said to me as to why I did not kill the child when he was just born".	4	8	4X11
"A child with albinism is just like any other child provided you follow advice on how to care for him".	4	8	4X13
"I was told that he should put-on long-sleeved clothes, sun hat and I should apply sun burn cream".	4	8	4X14
Mhuuu. I do not remember.	4	8	4X16
"I only remember the advice given at the hospital and I accepted it".	4	8	4X18
"I thank God that I just accepted my child at once"	5	9	5X1
"Something in me just told me to accept the child at once".	5	9	5X2
"They did not say anything to me or show me my baby but went straight to my mother and asked what they should do with the baby without my knowledge".	5	9	5X3

"In my mind, I think they may be some people who ask midwives to kill their children when they are born with albinism; maybe that's why nurses were seeking permission on what to do with my child".	5	9	5X4
"In my family, there was no mistake but my husband's family did not accept the child, they said I had slept with someone with albinism to give birth to the child. My husband sent me home to my parents for six months till they got back to their senses"	5	9	5X5
"I think they did so because my husband does not have albinism".		9	5X6
"I love my child but other people spit out and some parents tell their children to touch their hair when they see her".	5	9	5X7
"I think and I have heard that they do so to prevent their children from turning into a child with albinism"	5	9	5X10
"The six months separation from my husband was very painful to me and being accused of a thing I did not do (sleeping with another man with albinism) was a disgrace to me. I was also forced to put my child in a private school for safety reasons thou with difficulties in paying fees just to keep her on a nearer school to my area".	5	9	5X11
"It is my prayer that this child grows into a responsible person to put to into shame those who despises her".	5	10	5X12
"I just heard that its ge... or blood that resembles what....? Thus, what cause"	5	10	5X13
I was told nothing by the nurses, doctors after my "child was born".	5	10	5X14
"I have once heard from friends that people with albinism just disappear, they do not die. I have also heard from the radio that other people think people with albinism are a source of wealth as such they kill them or sell them. I have also heard that some people come like thieves at night but just to still a child with albinism and nothing else.	5	10	5X17
It made me realise that they were disappearing because they were killed or sold"	5	10	5X18
I live in fear, don't know what to do to protect my child."	5		
"I felt pain but later on accepted that it is God's creation".	6	11	6X1
"It is what God gave me"	6	11	6X2
"They looked surprised but did not tell me anything. I was only told how to care for my child at a certain age at the under-five clinic".	6	11	6X3
"Because of ignorance may be."	6	11	6X4
"They accepted her but some were saying "look at the white person" we are going to sell her".	6	11	6X5
"I have been despised that I and my children resemble a pig. I have another 18-year-old girl but she fears to date a normal man because she does not trust anyone and she struggles to get a job despite having a Malawi School Certificate of Education".	6	11	6X7
"May be because they think a person with albinism is not a human being, does not live long, just disappear"	6	11	6X8
"Some relatives call her names such as: napweri, mzungu"	6	11	6X9
"They think a person with albinism is different from a normal person".	6	11	6X10
"People say that they stopped eating pork because of me; that I resemble a pig. I have money problems, sometimes I cannot afford to buy hat, long sleeved clothes and I also struggle to find transport money to go the clinic to get sun cream".	6	12	6X11
"It pains me".	6	12	6X12
"A person with albinism is just like any human being".	6	12	6X13
"I was told nothing at the hospital regarding albinism after giving birth".	6	12	6X14
"I will tell hr that thus God created you"	6	12	6X15
"I heard from the Malawi broadcasting radio that people with albinism are human beings, they should not be isolated"	6	12	6X16
"I understood the message and I always take care of myself and my child".	6	12	6X17
"I accepted the information and I am always careful in whatever I do for fear of being killed".	6	12	6X18
"I was happy because that was what God gave me"	7	13	7X1
"I just thought that a child with albinism is just as any other child".	7	13	7X2
"I delivered through caesarean section and do not remember being told anything after waking up"	7	13	7X3

"I remember my mother was shocked with the appearance of my child and was just showing everyone in the room. Saying "look at the appearance of this baby.." but I told him that it was what God gave us. My sister-in-law laughed and accused me with another man with albinism"	7	13	7X5
"I think because it was her first time to see the child of that kind".	7	13	7X6
"People call my child "makobiri" meaning money. The say my child can be a source of money if I sell her. Some friends have suggested to me that hospital staff might have exchanged my child with the one I have".	7	13	7X7
"They do that just to despise me and my child".	7	13	7X8
"All is because we accepted her as a gift from God".	7	14	7X10
"In terms of sun burn cream, we are not given enough supply sometimes it does not last till the next appointment day, we spend a lot of transport coming to collect the cream, if they could consider giving us enough maybe it could be better".	7	14	7X11
"I am also scared of those people who call my child "money".	7	14	7X12
"I just heard that there is some paint in the abdomen .. but I have forgotten its name which is found in men, and when it is in large amount. I don't know what happens but, it can cause albinism".	7	14	7X13
"I was told nothing by the medical people, they just sent me to cotton weaving company where I got information on how to care for my child"	7	14	7X14
"Sometimes our community leader calls for a meeting for all people with albinism to advise us that we should not walk at night nor open the door for anybody at night. I also heard on the Malawi broadcasting radio yesterday that the chairperson of our association was found dead and buried but the police is still investigating".	7	14	7X16
"I make use of this information and do not allow my child to go far from my house."	7	14	7X17
"I accepted the child as a child without problems"	8	15	8X1
"I knew that he was a human being just like us".	8	15	8X2
"The midwives were surprised and said "the child is a human being but different from other children".	8	15	8X3
"I get despised. People call her napweri, hair like a doll and some friends isolate her"	8	15	8X7
"I think because they think an albinism is not a human being".	8	15	8X8
"Some people despise me that "how can I, black mother to give birth to a white child?"	8	15	8X9
"She has vision problems and I cannot afford glasses but the teacher helped by putting her in front to read easily on the board".	8	15	8X11
"It pains me but I just pray for protection from God".	8	15	8X12
"A person with albinism is a human being just like anybody, we only differ in complexion".	8	16	8X13
"I was told not to worry and not do anything to the child because she is a human being. Because some people think of killing a child just because he/she is born with albinism. I was advised to use sun cream and to protect his skin".	8	17	8X14
"I heard from the radio that people with albinism are also human beings, we should love and not I isolate them".	8	17	8X16
"I accepted it and got encouraged with the information".	8	17	8X17
"Let me say, I was worried about where I was going to get sun cream, because I see children of this kind develop sores on their skin".	9	17	9X1
"Because I have seen children of this type developing skin rashes"	9	17	9X2
"Aaaa!.. I cannot remember because I delivered through caesarean section, so I could not see".	9	17	9X3
"You know people talk, some were laughing that they cannot bear and keep a child with albinism".	9	17	9X5
"Lack of understanding and not knowing the truth about giving birth to a child with albinism".	9	17	9X6
"Some neighbours are good; they help me to take care of the child and advise me not to leave the child alone. One of my neighbours has a child with albinism and she is the one who informed me that free sun cream is provided at Queen Elizabeth Central Hospital dermatology clinic".	9	17	9X7

"I think it is because they also know people with albinism are at risk of being missing or killed and also because this other neighbour understands the challenge of raising a child with albinism"	9	17	9X8
"Just a day before yesterday I was in the house and could not see him when I came out, when I asked his friends, I was told he was following another man who asked him to go with him, I run after them with my neighbour and the man suddenly disappeared, when I asked my child who the man was, he just said that the man told the child that he is" a bwana", a Chichewa term meaning "sir". This made me more scared than before. I also have been buying sun cream small tube at MK3,500 and large tube at MM7,000 from a colleague with albinism not knowing its given for free at Queens Hospital. I have financial problems sometimes struggle to find transport money when going to collect sun cream".	9	17	9X11
"Let me just say people say it is caused by "mwanamphepo".	9	18	9X13
"I was not told anything when my child was born but I am not sure if my mother was told anything when she first came to the clinic to collect sun cream because I was sick and she came on my behalf".	9	18	9X14
"I just tell him that that is how you are, and those black in complexion also were born like that.	9	18	9X15
Yes, I do hear from the radio that we should not let our children move alone, because some people can kill them".	9	18	9X16
"I believed the story and I always hold my child by the hand when going anywhere: church, school or market".	9	18	9X17
"I realised that I cannot even trust my neighbours because they can turn against my child anytime."	9	18	9X18
"It was so painful being my first child, eventually I accepted the child"	10	19	10X1
"It was because of the gospel message that came on time, teaching about different gifts that people receive from God"	10	19	10X2
"Yes, there were Doctors who told me that my child had no problems and that I must take care of the child"	10	19	10X3
"My family accepted my child and they still love him but my husband and his family did not accept the child and their relationship with the child is not good up to now"	10	19	10X5
"I think and heard that they think I had slept with another man with albinism because the father is black in complexion"	10	19	10X6
"I do not sleep normally as you people do. I am scared especially at night thinking of what might happen when I am asleep. I have met a colleague at the clinic who was stabbed all over as he was trying to protect himself from people who wanted to cut his private part but failed because he fought with them and that... makes me more scared at night. I have also been accused of sleeping with another man and my marriage is affected; my husband asked me to choose between marriage and his own child of which I chose my child. My husband said plainly that he does not want this child".	10	19	10X7
"May be lack of understanding that it was not my choice to give birth to a child like this".	10	19	10X8
"Most people love him, I should not lie but some of his friends mock him, calling him Napweri and refuse to play with him. Some of my friends have directly asked me as to why I did or do not kill my child and, I do not want to be anywhere close to them. Some neighbours have been discouraging me from going to the hospital for sun cream, they believe the hospital people have evil plans so they are attracting people with free sun cream but surprisingly this is the sixth year I have been coming and nothing has happened to my child"	10	20	10X9
"May be that is what they know and believe".	10	20	10X10
"The child's father and his family do not support him financially; he only is supported by my parents. He also does not see properly but I requested the teacher that maybe he should make his writings a little bigger".	10	20	10X11
"I always ask myself a question of what exactly the cause of this is".	10	20	10X12
"I do not know or understand what exactly happens and I always ask myself that same question".	10	20	10X13
"Like I said earlier on, I was just told that the child is normal; there is any problem with him".	10	20	10X14

"I always tell him that "we are the same; we both have arms and that your friends are just jealous of your appearance"	10	20	10X15
"I heard from the radio about people cutting and selling private parts of people with albinism".	10	20	10X16
"I believed the story because it was from the radio".	10	21	10X17
'I am so scared but I keep on Praying with my mother for protection and we encourage each other"	10	21	10X18

## APPENDIX 11: SEARCHING FOR THEMES

Significant Statements	Formulated meanings
“After my child was born the nurse told me that it was born with albinism and I accepted it without problems”. Transcript 1, page 1 lines 1X1.	Mother indicates acceptance of her child born with albinism.
“I remember they were only surprised as the child was coming out, they thought it was something but after birth they did not look surprised”. Transcript 1, Page1, lines, 1X3	Nurses and midwives were surprised with the appearance but later realised it was born with albinism.
“This was because “this thing” does not happen often, so it was strange to them”. Transcript 1, Page 1, lines 1X4	Mother believes that children with albinism are rarely found and that it could be the first time for midwives to deliver a child with albinism.
“Most of my relatives were disappointed though some supported me because in our family I was the first one to give birth to a child of this kind”. Transcript 1 page 1, lines 1X5.	Mother indicated that some relatives accepted and supported her while others were disappointed because there was no history of albinism in their family.
“I think because children with albinism are difficult to take care of, they need to be protected from the sun because when they are exposed to sun their skin gets destroyed. It could also be because people of this kind are rarely found and maybe it was their first time to see a child of this kind”. Transcript 1 page 1, lines 1X6	Mother indicates awareness of physical problems associated with children born with albinism but also realizes albinism is not common considering that nurses are surprised with the appearance of the baby.
“I take good care of this child but his friends isolate him because of his appearance. It could be possible that people are not happy because of his appearance. some relatives and friends segregate the child sometimes”. Transcript 1, page 1, lines 1X7 and 1X9	Mother indicates love for her child. People isolate a child because of his appearance and the mother perceives segregation.
“Eisha! I feel worried especially when I hear stories of people with albinism being abused, I feel sorry for myself and scared of evil people who keep on following me without my knowledge”. Transcript 1 page 2, lines 1X11. “I feel scared but I put God first so that he should protect my child from people with evil thoughts who keep on following me without my knowledge”. Transcript 1, page 2, lines 1X12	Mother is worried, scared and feels sorry for herself after realising that people with albinism are abused and killed. Mother believes that only God can protect her child.
“There is no difference between a person with albinism and any other person because when injured, we feel the same pain”. Transcript 1 page 2, line 1X13	Mother perceives a child with albinism just like any human being.
“I was told that this child is different from any other child and needs to be protected. I cannot say much because at the hospital, I was not told why I gave birth to this kind of a child”. Transcript 1 page 2-line 1X14	Mother has information on how to care for the child but lacks awareness of what caused the albinism itself.
“I just heard that for a child to be born with Albinism, there is a small problem found in a woman or man but I did not hear properly because I got there when the programme was coming to an end”. Transcript 1, page 2, line 1X16. “My understanding is that, this child is the same as any other child and deserves love and care from me and his father”. Transcript, 1 page 2, line 1X17	Mother understands that albinism is caused by a problem found in a woman or man. but does not reckon the problem. People should not discriminate a child with albinism because of the appearance than a normal child.
“I was so disappointed when I saw the child but my mother encouraged me that God cannot create something that is bad, I later accepted”. Transcript 2, page 3-line 2X1. “I was disappointed because I got pregnant and left school and only to give birth to this kind of a child”. Transcript 2 page 3, line 2X2	Mother felt disappointed after giving birth to a child with albinism but got assured encouraged and supported by her mother. Mother felt like she lost her self-esteem. Mother felt she did not deserve to give birth to a child with albinism.
“I think they were surprised because it could be their first time to see a child with albinism but also with no skin rashes or black spots”. Transcript 2, page 3, lines 2X4. “They did so because it was surprising and strange to	Mother feels that society is not used to children with albinism because they are rarely found. People think that all children with albinism are born with rashes.

them'. transcript, 2 page 3, line 2X6." It could be that it is strange to them". Transcript 2, page 4, line 2X10	
"Some of them accepted him but some mocked me that how could I give birth to a child who stinks or smells like the sun he is going to bring calamity to us". Transcript 2 page 3, line 2X5	some people understand that a person with albinism is a human being, others think people with albinism smell like sun and others believe that having albinism brings calamity to the society.
"I have been despised that I gave birth to a child that smells like sun. His friends mock him, isolate him and call him a white person who smell like the sun to a child that smells like sun. He is segregated by friends at school to the point that he refuses to go to school at times. When he meets pregnant women, they chase him away because they are afraid of giving birth to a child with albinism". Transcript 2, page 3, Line 2X7 and 2X9	A child with albinism is mocked and isolated because his friends believe that he smells like sun. Pregnant women, believe that they may deliver a baby with albinism by staying closer to child. Mother indicates that friends segregate her child and he refuses to go to school.
"I feel pain but I just ignore what people say because God cannot create a bad thing". Transcript 2, page 4, line 2X12.	Mother expresses the pain she has gone through.
"My understanding is that a child with albinism is just like any person". Transcript 2, page 4-line 2X13. "They just told me to take care of the child because he is just like any other human being".	Mother understand a child with albinism like any normal child. Mother is informed on how to protect her child from sunlight but lack information on the "real cause" of albinism.
"He keeps on asking me why he looks different from me and I tell him that he is white person and is good looking than me" transcript 2, page 4, line, 2X15	Mother does not know what to tell her child, she tells her child that he is a white person.
"I just heard that we should take care of our children, they should not be walking alone. I always follow my child when he is playing, it's like I am also playing to ensure his safety". Transcript 2 page 4, line: 2X16. "I understood well and I always follow my child when he is playing, it is like I am also playing to ensure his safety but the child it also affected the child because sometimes they refuse going to school for fear of being killed". Transcript 2, page 4, lines: 2X17. "I accepted it and am used to following my child wherever he is playing to ensure his safety". Transcript 2, page 4, lines: 2X18	Mother and her child with albinism live in fear and lack peace of mind.
"When I saw my child, there was nothing that surprised me, I just accepted him". Transcript 3, page 5, line: 3X1. "Yes, I remember when he was born everyone was happy to see him, no one looked surprised". Transcript 3, page5, line 3X3	Mother indicates that she accepted her child with no problems and people were supportive.
"I think they did not want to disappoint me or, they were also interested with how the child was looking". Transcript 3, page 5, line: 3X4.	Some family members are supportive.
"The main challenge I have gone through is losing my marriage. My ex- husband's relatives were talking a lot because my husband does not have albinism so I decided to get out of marriage and take care of my child". Transcript 3, page 6, line:3X11	Mother has suffered abuse from husband and his family members to the point of being divorced. People think only people who have albinism can give birth to a child with albinism.
"My understanding is that there are several causes of albinism but what I remember is that when genes are weak, a child fails to develop the top layer skin". Transcript 3, page 6, lines:3X13	Mother understands albinism as something caused by weak genes which fail to development of the top layer skin.
"I was told that my child had weak genes and failed to develop skin but he is just as any other person. I was given an example that if a normal person has an open wound, a white skin appears first before blood comes out. That is what I grabbed". Transcript 3, page 6. line: 3X14	Mother got information that albinism is caused by weak genes from health workers.
"He once asked me that question but because he is a child, I just told him that" ndiwe mzungu kapena mwenye" (you are a white person or an Indian) and he believed because he finds his skin similar to those people". Transcript 3, page 6, line:3X15.	Mother tells her child that she is an Indian "Mwenye" or white person "mzungu"

<p>"Eeee... I have never heard anything from the radio or Television apart from the doctors or, if I heard then I might have forgotten". Transcript 3, page 6, lines:3X16. "I should just say I have never heard anything". Transcript 3, page 6, line: 3X17.</p>	<p>Mother has never had information regarding albinism from any other sources other than the health workers.</p>
<p>"I just felt that it was a gift from God". Transcript 4, page 7, line: 4X1 "I just felt that it was a gift from God".</p>	<p>Mother feels that her child is a gift from God</p>
<p>"They accepted him and advised me to start collecting sunburn cream from the hospital". Transcript 4, page 7, lines: 4X3</p>	<p>Mother shows that nurses accepted the child and advised mother to protect the child from sun.</p>
<p>"May be its because of their understanding, they do not see the importance of a person with albinism". Transcript 4, page 7, line: 4X8.</p>	<p>Mother perceive that other people underlet her because they see a child with albinism as of no potential.</p>
<p>"I have no problem with my neighbours". Transcript 4, page 7, line: 4X9</p>	<p>Mother indicates that her neighbours show love and accept her child.</p>
<p>"They do not differentiate a child with albinism with a normal child". Transcript 4, page 7, line: 4X10</p>	<p>Neighbours accept a child with albinism as any normal child.</p>
<p>"There are times when some people have said to me as to why I did not kill the child when he was just born". Transcript 4, page 8, line 4X11</p>	<p>Some people believe that children with albinism need to be killed immediately after birth.</p>
<p>"A child with albinism is just like any other child provided you follow advice on how to care for him". Transcript 4, page, 8-line 4X13</p>	<p>Mother describes her child as any normal child as long as he is cared accordingly.</p>
<p>"I was told that he should put-on long-sleeved clothes, sun hat and I should apply sun burn cream". Transcript 4, page 8, line 4X14</p>	<p>Mother was educated on sun preventive measures and where to access cream.</p>
<p>"Mhuuu.. I do not remember". Transcript 4, page 1, line 4X16. "I only remember the advice given at the hospital and I accepted it". Transcript 4, page 8, line: 4X18</p>	<p>Mother does not have information from any other sources besides the hospital.</p>
<p>"I thank God that I just accepted my child at once" Transcript 5 page 9, line 5X1</p>	<p>Acceptance of the child is associated with divine power.</p>
<p>"Something in me just told me to accept the child at once". Transcript 5 page 9, line: 5X2</p>	<p>Mother indicates that motherly love helped her to accept the child at once.</p>
<p>"They did not say anything to me or show me my baby but went straight to my mother and asked what they should do with the baby without my knowledge". Transcript 5, page 9, lines 5X3</p>	<p>Mother feels that she was not involved by the midwives in the decision of her child's wellbeing.</p>
<p>"In my mind, I think they may be some people who ask midwives to kill their children when they are born with albinism; maybe that's why nurses were seeking permission on what to do with my child". Transcript 5, page 9 lines: 5X4</p>	<p>Mother believe that some midwives and nurses may be involved in helping mothers kill their children born with albinism.</p>
<p>"In my family, there was no mistake but my husband's family did not accept the child, they said I had slept with someone with albinism to give birth to the child. My husband sent me home to my parents for six months till they got back to their senses". Transcript 5 page 9, lines 5X5</p>	<p>Mother shows that her family accepted the child and supported her while the husband and his family accused the woman of cheating him with another man with albinism. People think that only people with albinism can give birth to a child with albinism.</p>
<p>"I think they did so because my husband does not have albinism". Transcript 5, page 9 line: 5X6.</p>	<p>Husband and family were not supportive because they were not aware of the cause of albinism.</p>
<p>"I love my child but other people spit out and some parents tell their children to touch their hair when they see her". Transcript 5, page 9, lines 5X7</p>	<p>People believe that if one doesn't spit out or touch hair after meeting a person with albinism, he/she acquires albinism.</p>
<p>"I think and I have heard that they do so to prevent their children from turning into a child with albinism". Transcript 5, page 9, lines: 5X8</p>	<p>People believe they can prevent their children from acquiring albinism. People regard albinism as a contagious disease.</p>
<p>"The six months separation from my husband was very painful to me and being accused of a thing I did not do (sleeping with another man with albinism) was a disgrace to me. I was also forced to put my child in a private school for safety reasons thou with difficulties in paying fees just to keep her on a nearer school to my area". Transcript 5 page 9, lines: 5X11</p>	<p>Mother experienced pain, anger, shame and emotional trauma after the birth of her child. Mother experiences financial constraints just to keep her child safe.</p>
<p>"It is my prayer that this child grows into a responsible person to put to into shame those who despises her". Transcript 5, page 10, lines 5x12</p>	<p>Mother is working hard to educate her child so that society should be able to realise that there is potential in a child with albinism just like in any normal child.</p>

<p>"I just heard that its ge... or blood that resembles what...? Thus, what cause..." Transcript 5, page 2, lines: 5X13</p>	<p>Mother does not understand clearly the cause of albinism</p>
<p>"I was told nothing by the nurses, doctors after my child was born". Transcript 5, page 10, lines 5X14</p>	<p>No information regarding albinism was given to the mother after birth of her child by nurses or Doctors</p>
<p>"I have once heard from friends that people with albinism just disappear, they do not die. I have also heard from the radio that other people think people with albinism are a source of wealth as such they kill them or sell them. I have also heard that some people come like thieves at night but just to still a child with albinism and nothing else. I also heard from friends that someone sold her own sisters' daughter". Transcript 5, page 10 lines: 5X14</p>	<p>Mother indicated that society think that people with albinism are spirits or ghosts, disappear mysteriously. People with albinism are hunted and abducted even from their houses because they are considered as a source of wealth. Some children with albinism are sold by their relatives.</p>
<p>"It made me realise that they were disappearing because they were killed or sold". Transcript 5, page 10, lines: 5X17</p>	<p>Mother realises that disappearing of children with albinism is associated with the killing and selling of their body parts.</p>
<p>"I felt pain but later on accepted that it is God's creation". Transcript 6, page 11, lines 6X1</p>	<p>Mother felt pain for giving birth to a child with albinism but later accepted.</p>
<p>"It is what God gave me". Transcript 6, page 11, lines: 6X2</p>	<p>God knows why a child was born with albinism</p>
<p>"They looked surprised but did not tell me anything. I was only told how to care for my child at a certain age at the under-five clinic". Transcript 6, page 11, lines: 6X3</p>	<p>Some health workers are not fully aware of how a baby born with albinism looks like.</p>
<p>"Because of ignorance may be..." Transcript 6, page 11, lines:6X4</p>	<p>People lack understanding of albinism.</p>
<p>"They accepted her but some were saying "look at the white person" we are going to sell her". Transcript 6, page11, lines 6X5</p>	<p>Mother indicated that some family members were supportive while others despised her child by calling her names like "white person" People think the mother had slept with a person with a white man. People think children with albinism can be sold.</p>
<p>"I have been despised that I and my children resemble a pig. I have another 18-year-old girl but she fears to date a normal man because she does not trust anyone and she struggles to get a job despite having a Malawi School Certificate of Education". Transcript 6, page 11, lines: 6X6</p>	<p>People believe that people with albinism are pigs. Mother indicates that her girl child fears to date a normal man due to loss of trust in people. Mother thinks that her daughter struggles to get a job of her of her scope due to her condition.</p>
<p>"May be because they think a person with albinism is not a human being, does not live long, just disappear". Transcript 6, page 11, lines:6X7</p>	<p>People believe that a person with albinism is a ghost and not human.</p>
<p>"Some relatives call her names such as: napweri, mzungu". Transcript 6, page 11, lines 6X8</p>	<p>Mother indicates that some relatives call her child "Napweri "meaning dry pigeon peas.</p>
<p>"They think a person with albinism is different from a normal person". Transcript 6, page 11, lines:6X9</p>	<p>People regard a person with albinism as a ghost.</p>
<p>"People say that they stopped eating pork because of me; that I and my child resemble a pig. I have money problems, sometimes I cannot afford to buy hat, long sleeved clothes and I also struggle to find transport money to go the clinic to get sun cream". Transcript 6, page 12, lines: 6X10</p>	<p>People regard a person with albinism as a pig and this make them loose appetite for pork. Mother and her child are called pigs by relatives and friend. Mother shows that she encounters financial constrains at times.</p>
<p>"It pains me". Transcript 6, page 12, lines: 6X11</p>	<p>Mother expresses the feeling of pain.</p>
<p>"A person with albinism is just like any human being". Transcript 6, page 12, lines:6X13</p>	<p>Mother believes a person with albinism is just like any human being.</p>
<p>"I was told nothing at the hospital regarding albinism after giving birth". Transcript 6, page 12, lines: 6X14</p>	<p>Health workers did not counsel or explain anything about albinism after birth.</p>
<p>"I heard from the Malawi broadcasting radio that people with albinism are human beings, they should not be isolated". Transcript 6, page 12, lines: 6X16</p>	<p>Malawi Broadcasting radio promotes albinism awareness by telling people that people with albinism are human beings.</p>
<p>"I understood the message and I always take care of myself and my child. Transcript 6, page 12, lines: 6X16 I accepted the information and I am always careful in whatever I do for fear of being killed". Transcript 6, page 12, lines: 6X17</p>	<p>Mother is informed and always ensure safety of her child.</p>

"I accepted the child as a child without problems". Transcript 8, page 15, lines: 8X1	Mother indicates love and acceptance of her child.
"I knew that he was a human being just like us". Transcript 8, page 15, lines: 8X2	Mother accepts her child just like any normal child.
"The midwives were surprised and said "the child is a human being but different from other children". Transcript 8, page 15, lines: 8X3	Mother shows that midwives did not give a clear explanation of condition of the child.
"I get despised. People call her napweri, hair like a doll and some friends isolate her". Transcript 8, page 15, line: 8X6	Mother and child are called names like 'napweri' People think a child with albinism is a doll.
"I think because they think an albinism is not a human being". Transcript 8, page 15, lines: 8X7	Mother thinks people regard a person with albinism as not human.
"Some people despise me that "how can I, black mother to give birth to a white child?" Transcript 8, page 15, line: 8X8	Some people think mother slept with a white person or a man with albinism.
"She has vision problems and I cannot afford glasses but the teacher helped by putting her in front to read easily on the board". Transcript 8, page 15, lines: 8X10	A child has poor sight, mother has financial problems and teacher is supportive.
"It pains me but I just pray for protection from God". Transcript 8 page 15 lines:8X11	Mother feels pain and seeks for God's protection.
"A person with albinism is a human being just like anybody, we only differ in complexion". Transcript 8, page 16, lines: 8X13. "I was told not to worry and not do anything to the child because she is a human being. Because some people think of killing a child just because he/she is born with albinism. I was advised to use sun cream and to protect his skin". Transcript 8, page 16 lines: 8X14." I heard from the radio that people with albinism are also human beings, we should love and not I isolate them". Transcript 8. Page 16, lines: 8X16,	Mother believes that her child with albinism is just like any human being despite a different appearance. Health workers supported the woman, advised her to protect her child's skin from the sun and advised her not to harm the child. Mother indicates that some people kill their children because they have albinism. Mother got some information that people with albinism are also human beings from the radio.
"I accepted it and got encouraged with the information". Transcript 8, page 16, lines: 8X16	Information from the radio encouraged the mother.
"Let me say, I was worried about where I was going to get sun cream, because I have seen children of this kind develop sores on their skin". Transcript, 9, page 17, lines: 9X1	Mother was worried about how she would protect her child from skin problems because of her previous experience regarding skin problems associated with albinism.
"Because I have seen children of this type developing skin rashes". Transcript 9, page 17, lines: 9X2	Mother was worried because of her previous experience about skin problems which affect children with albinism.
"Aaaa!.. I cannot remember because I delivered through caesarean section, so I could not see". Transcript 9, page, 17, lines: 9X3	Mother does not remember having being told anything by health workers at the hospital after Birth.
"You know people talk, some were laughing that they cannot bear and keep a child with albinism". Transcript 9, page 17, lines: 9X5.	People laughed and accused the woman for keeping her child with albinism alive.
"Lack of understanding and not knowing the truth about giving birth to a child with albinism". Transcript 9, page 17, lines:9X6.	People lack awareness of the cause albinism.
"Some neighbours are good; they help me to take care of the child and advise me not to leave the child alone. One of my neighbours has a child with albinism and she is the one who informed me". Transcript 9, page 17 lines: 9X7.	Some neighbours are supportive in terms of caring and ensuring safety of the child.
"I think it is because they also know people with albinism are at risk of being missing or killed and also because this other neighbour understands the challenge of raising a child with albinism". Transcript 9, page 17, lines: 9X8	Mother indicates that neighbours are supportive because they know the fate of children with albinism, it could be because they perceive people with albinism as human beings Another neighbour is more supportive because she has experienced raising a child with albinism.
"Just a day before yesterday I was in the house and could not see him when I came out, when I asked my friends, I was told he was following another man who asked him to go with him, I run after them with my neighbour and the man suddenly disappeared, when I asked my child who the man was, he just said that the man told the child that he is" a bwana", a Chichewa term meaning "sir". This made me more scared than before. I also have been buying sun	Mother expressed her fears and worries because her child almost disappeared a day prior the interview. Some unknown man wanted to steal her child. Mother expresses her concern for spending money on sun cream which she could get for free if she was informed. Some people use the sun cream meant for their skin as a source of money.

<p>cream small tube at MK3, 500 and large tube at MM7,000 from a colleague with albinism not knowing it was given for free at Queens Hospital. I have financial problems sometimes struggle to find transport money when going to collect sun cream". Transcript 9, page 17, lines: 9X9</p> <p>"Let me just say people say it is caused by "mwanamphepo". Transcript 9 page 18, lines: 9X13</p>	<p>Mother understand albinism as a condition caused by mwanamphepo.</p>
<p>"I was not told anything when my child was born but I am not sure if my mother was told anything when she first came to the clinic to collect sun cream because I was sick and she came on my behalf". Transcript 9, page 18, lines: 9X14</p>	<p>No information regarding albinism was given to the mother by health workers after birth.</p>
<p>"I just tell him that it is how you are, and those black in complexion also were born like that". Transcript 9, page 18, lines: 9X15</p>	<p>Mother tells her child that he is just like any human being despite a difference in complexion.</p>
<p>"Yes, I do hear from the radio that we should not let our children move alone, because some people can kill them. I just heard from the radio a day before yesterday that a boy went missing on Independence Day (6/7/2018) and was found dead and the police are suspecting the step father but both parents are arrested. It is scary". Transcript 9, page 18, lines: 9X16.</p>	<p>Mothers of children with albinism are warned to ensure that their children are accompanied by someone old wherever they go. Some children with albinism are suspected to be sold and killed by close relatives.</p>
<p>"I believed the story and I always hold my child by the hand when going anywhere: church, school or market". Transcript 9, page 18. Lines: 9X17</p>	<p>Mother ensures safety of her child always.</p>
<p>"I realised that I cannot even trust my neighbours because they can turn against my child anytime." Transcript 9, page 18, lines 9X18.</p>	<p>Mother indicates that she cannot even trust neighbours cannot be trusted.</p>
<p>"It was so painful being my first child, eventually I accepted the child". Transcript 10, page 19, lines: 10X1</p>	<p>Mother experienced pain especially being her first child but eventually accepted her child.</p>
<p>"It was because of the gospel message that came on time, teaching about different gifts that people receive from God". Transcript 10, page 19, lines: 10X2.</p>	<p>Mother shows that the gospel message that came on time, helped her to accept her child.</p>
<p>"Yes, there were Doctors who told me that my child had no problems and that I must take care of the child". Transcript 10, page 19, lines 10X3</p>	<p>Doctors told the mother that her child had no problems.</p>
<p>"My family accepted my child and they still love him but my husband and his family did not accept the child and their relationship with the child is not good up to now". Transcript 10, page 19, lines: 10X5</p>	<p>Mother shows that her family accepted the child but the husband and family did not.</p>
<p>"I think and heard that they think I had slept with another man with albinism because the father is black in complexion". Transcript 10, page 19, lines 10X6</p>	<p>The husband's family think the wife cheated on the husband.</p>
<p>"I do not sleep normally as you people do. I am scared especially at night thinking of what might happen when I am asleep. I have met a colleague at the clinic who was stabbed all over as he was trying to protect himself from people who wanted to cut his private part but failed because he fought with them and that... makes me more scared at night. I have also been accused of sleeping with another man and my marriage is affected; my husband asked me to choose between marriage and his own child of which I chose my child. My husband said plainly that he does not want this child". Transcript 10, page 2, lines:10X7</p>	<p>Mother lacks proper sleep due to fear of what might happen at night. Her fear increases when she remembers a colleague, she met at the clinic with stabbed wounds due to fighting with people who wanted to chop some of his private parts in his house at night. People believe that private parts of people with albinism are a source of wealth. Mother indicates that she was abandoned after choosing to keep her (their) child alive. Husband plainly said he did not want a child with albinism and asked mother to choose between a child and her marriage.</p>
<p>"May be lack of understanding that it was not my choice to give birth to a child like this". Transcript 10, page 19, lines: 10X8</p>	<p>People lack understanding of the cause of albinism.</p>
<p>"Most people love him, I should not lie but some of his friends mock him, calling him Napweri and refuse to play with him. Some of my friends have directly asked me as to why I did or do not kill my child and, I do not want to be anywhere close to them. Some neighbours have been discouraging me from going to the hospital for sun cream, they believe the hospital people have evil plans so they are attracting people with free sun cream</p>	<p>Some people are supportive but others directly accuse her for not killing her child up to now. Some neighbours think the hospital supply free sun cream to attract people with albinism so that they can sell or kill them. Mother isolate herself from neighbours for fear of evil advice.</p>

but surprisingly this is the sixth year I have been coming and nothing has happened to my child". Transcript 10, page 20, lines: 10X9.	
"May be that is what they know and believe". Transcript 10, page 20, lines: 10X10.	People believe that health workers are involved in the stealing and killing of people with albinism.
"The child's father and his family do not support him financially; he is only supported by my parents. He also does not see properly but I requested the teacher that maybe he should make his writings a little bigger". Transcript 10, page 20, lines: 10X11.	Mother indicate that only her family support the child financially but the father abandoned him. Her child has poor eye sight but the teacher offers support.
"I always ask myself a question of what exactly the cause of this is". Transcript 10, page 20, lines: 10X12.	Mother is not aware of the cause of albinism.
"I do not know or understand what exactly happens and I always ask myself that same question". Transcript 10, page 20, lines: 10X12 and 10X13	Mother has a lack information about causes albinism.
"Like I said earlier on, I was just told that the child is normal; there is no any problem with him". Transcript 10, page 20, lines: 10X14	Health workers regarded albinism as normal.
"I always tell him that "we are the same; we both have arms and that your friends are just jealous of your appearance". Transcript 10, Page 20, lines: 10X15	Mother tells her child that he is just like any child despite appearance, they have similar body parts.
"I heard from the radio about people cutting and selling private parts of people with albinism". Transcript 10, page 20, lines: 10X16	Mother mentioned that she heard stories of people's private parts being chopped and sold the Malawi broadcasting cooperation radio. People with albinism are killed because they are considered a source of money.
"I believed the story because it was from the radio". Transcript 10, page 20, lines: 10X17.	Mother believes the story of killing people with albinism is valid because it is from the reliable source.
"I am so scared but I keep on Praying with my mother for protection and we encourage each other". Transcript 10, page 21, lines: 10X18	Mother is scared but she is supported by her mother and strengthened by prayer.
"I was happy because that was what God gave me". Transcript 7, page 13, lines 7X1	Mother shows love and acceptance of her child.
"I just thought that a child with albinism is just as any other child". Transcript 7, page 13, lines: 7X2	Mother perceive her child just like any normal child.
"I delivered through caesarean section and do not remember being told anything after waking up". Transcript 7, page, 13, lines: 7X3	Mother indicates that she was not given any information regarding her child by health workers after birth.
"I remember my mother was shocked with the appearance of my child and was just showing everyone in the room. Saying "look at the appearance of this baby..." but I told him that it was what God gave us. My sister-in-law laughed and accused me with another man with albinism". Transcript 7, page 13, lines: 7X5.	mother was surprised with the child to the point of showing everyone in the room. Her sister-in-law laughed at her and accused her of cheating on her husband with another man with albinism.
"I think because it was her first time to see the child of that kind". Transcript 7, page 13, lines: 7X6.	Her mother was surprised because there was no history of albinism in their family.
"People call my child "makobiri" meaning money. The say my child can be a source of money if I sell her. Some friends have suggested to me that hospital staff might have exchanged my child with the one I have". Transcript 7, page 13, lines: 7X7.	People think a child with albinism can be a source of wealth. Some people think hospital staff exchanged her child with someone's with albinism. Some people believe that only parents with albinism give birth a child with albinism.
"They do that just to despise me and my child". Transcript 7, page 13, lines: 7X8.	People despise the mother and the child.
"All is because we accepted her as a gift from God". Transcript 7, page 13, lines: 7X10.	
"In terms of sun burn cream, we are not given enough supply sometimes it does not last till the next appointment day, we spend a lot of transport coming to collect the cream, if they could consider giving us enough maybe it could be better". Transcript 7, page 14, lines: 7X11.	Inadequate supply of sun cream makes her spend a lot of money due to multiple trips to the hospital within a short period of time.
"I am also scared of those people who call my child "money". Transcript 7, page 14, lines: 7X12.	Mother feels scared when her child is called money.

<p>“I just heard that there is some paint in the abdomen. but I have forgotten its name which is found in men, and when it is in large amount. I don’t know what happens but, it can cause albinism”. Transcript 7, page 14, lines:7X13.</p>	<p>Mother heard that albinism is caused by paint found in men.</p>
<p>“I was told nothing by the medical people, they just sent me to cotton weaving company where I got information on how to care for my child”. Transcript 7, page 14, lines:7X14.</p>	<p>Mother got no information regarding albinism from hospital after birth. Mother got information on how to care for a child with albinism from the cotton weaving company.</p>
<p>“Sometimes our community leader calls for a meeting for all people with albinism to advise us that we should not walk at night nor open the door for anybody at night. I also heard on the Malawi broadcasting radio yesterday that the chairperson of our association was found dead and buried but the police is still investigating”. Transcript 7, page 14. Lines:7X16.</p>	<p>Mother got some information regarding the safety of people from her community leader. Mother heard a story of one person with albinism who was killed from the Malawi Broadcasting cooperation radio.</p>
<p>“I make use of this information and do not allow my child to go far from my house”. Transcript page 14, lines: 17.</p>	<p>Mother ensures safety of her child always by keeping her child close.</p>

## APPENDIX 12: REVIEWING THEMES, CATEGORISING THEMES AND CLUSTER THEMES

Formulated meanings	Theme clusters	Emergent theme
<p>Mother feels scared when her child is called money. Transcript 7, page 14, lines: 7X12 Her fear increases when she remembers a colleague, she met at the clinic with stabbed wounds due to fighting with people who wanted to chop some of his body parts in his house at night Transcript 10, page 19, and lines: 10X7. Mother listened to a story of one person with albinism who was killed from the Malawi Broadcasting cooperation radio. Transcript 7, page 14. Lines:7X16 Mother is worried, scared and feels sorry for herself after realising that people with albinism are abused and killed. Transcript 1 page 2, lines 1X11 and 1X12. Mother lacks proper sleep due to fear of what might happen at night. Her fear increases when she remembers a colleague, she met at the clinic with stabbed wounds due to fighting with people who wanted to chop some of his body parts in his house at night Transcript 10, page 19, and lines: 10X7. Mother isolates herself from neighbours for fear of evil advice. Transcript 10, page 20, lines:10X9 People laughed and accused the woman for keeping her child with albinism alive. Transcript 9, page 17, lines: 9X5. Mother expressed her fears and worries because her child almost disappeared a day prior the interview. Mother indicates that she cannot even trust neighbours cannot be trusted. Transcript 9, page 18, lines 9X16. People with albinism are hunted and abducted even from their houses because they are considered as a source of wealth. Transcript 5, page 10, lines: 5X14.</p> <p>People with albinism are hunted and abducted even from their houses because they are considered as a source of wealth. Transcript 5, page 10, lines: 5X14</p>	<p><i>Killings of people with albinism</i></p>	<p><b>STIGMATISATION, DISCRIMINATION AND HARM</b></p>
<p>Mother indicated that some relatives accepted and supported her while others were <u>disappointed</u> because there was no history of albinism in their family. Transcript 1 page 1, lines 1X5 Her mother was surprised because there was no history of albinism in their family. Transcript 7, page 13, lines: 7X6</p> <p>Mother has suffered abuse from husband and his family members Transcript 3, page 6, line:3X11. Mother indicated that some family members were supportive while others despised her child by calling her names like “white person” Transcript 6, page 11, lines 6X5</p> <p>Mother shows that her family accepted the child, but the husband and family did not Transcript 10, page 1, lines: 10X5. The husband’s family think the wife cheated on the husband. Transcript 10, page 1, lines: 10X6 Mother has suffered abuse from husband and his family members to the point of being divorced. Transcript 3, page 6, line: 3X11 Mother indicates that she was abandoned after choosing to keep her (their) child alive. Husband plainly said he did not want a child with albinism and asked mother to choose between a child and her marriage. Transcript 10, page 19, lines: 10X7.</p>	<p><i>Rejection from family members and friends and husbands</i></p>	<p><b>STIGMATISATION, DESCRIMANATIO N,</b> <b>CONT’D</b></p>
<p>Others think that people with albinism smell like sun and others believe that having albinism brings calamity to the society. Transcript 2 page 3, line 2X5. pregnant women believe that they may deliver a baby with albinism by staying closer to child with albinism. Transcript 2, page 3 Line 2X7 and 2X9. People think only people who have albinism can give birth to a child with albinism Transcript 3, page 6, line: 3X11.Mother feels that her child is a gift from God. Transcript 4, page 7, line: 4X1. Some people believe that children with albinism need to be killed Mother</p>	<p><i>Labelling of people with albinism</i></p>	<p><b>STIGMATISATION, DISCRIMINATION, &amp; HARM</b> <b>CONT’D</b></p>

indicates that some relatives call her child “Napweri “meaning dry pigeon peas. Transcript 6, page 11, lines 6X8. Some people believe that only parents with albinism give birth a child with albinism. Transcript 7, page 13, lines:7X7. People think only people who have albinism can give birth to a child with albinism Transcript 3, page 6, line: 3X11.Mother feels that her child is a gift from God. Transcript 4, page 7, line: 4X1. Some people believe that children with albinism need to be killed immediately after birth. Transcript 5, page 9, lines: 5X4. People think that only people with albinism can give birth to a child with albinism. Transcript 5 page 9, lines 5X5. People believe that if one doesn’t spit out or touch hair after meeting a person with albinism, he/she acquires albinism. Transcript 5, page 9, lines: 5X7. People believe they can prevent their children from acquiring albinism Transcript 5, page 9, lines: 5X8. People regard albinism as a contagious disease. Transcript 5, page 9 lines: 5X8 Mother indicated that society think that people with albinism are spirits or ghosts, disappear mysteriously Transcript 5, page 10, lines: 5X14. People think children with albinism can be sold. Transcript 7, page 13, line: 7X7. People believe that a person with albinism is a ghost and not human. Transcript 6, page 11, lines:6X7 and Transcript 6, page 11, lines:6X9. People regard a person with albinism as a pig and this make them loose appetite for pork. Transcript 6, page 12, lines: 6X10. People think a child with albinism is a doll. Transcript 8, page 1, line: 8X6. Mother thinks people regard a person with albinism as not human. Transcript 8, page 15, lines: 8X7. Transcript 8, page 15, line: 8X8. Some people think mother slept with a white person or a man with albinism. Transcript 8, page 15, line: 8X8

Mother perceive that other people underlet her because they see a child with albinism as of no potential. Mother expresses the feeling of pain Transcript 6, page 11, lines: 6X11 Mother felt disappointed after giving birth to a child with albinism but got assured encouraged and supported by her mother. Mother indicates that her girl child fears to date a normal man due to loss of trust in people. Transcript 2, page 3-line 2X1. Mother thinks that her daughter struggles to get a job of her scope due to her condition. Transcript 6, page 11, lines: 6X6. Mother felt like she lost her self-esteem.

Mother felt she did not deserve to give birth to a child with albinism Transcript 2, page 3-line 2X1. Transcript 3, page 6, line: 3X11.Mother feels that she was not involved by the midwives in the decision of her child’s wellbeing. Transcript 5, page 9, lines 5X3. Her mother was surprised because there was no history of albinism in their family. Transcript 7, page 13, lines: 7X6. Mother shows that her family accepted the child and supported her while the husband and his family accused the woman of cheating him with another man with albinism. Transcript 5 page 9, lines 5X5. Husband and family were not supportive because they are not aware of the cause of albinism. Transcript 5, page 9-line 5X6. Mother experienced pain, anger, shame and emotional trauma after the birth of her child. Most relatives supported her. Transcript 1 page 1, lines 1X5. some people understand that a person with albinism is a human being. Transcript 2 page 4, line 2X5. Some people love and accept her. Transcript 3, page 1, line: 3X4. Neighbours accept a child with albinism as any normal child. Transcript 4, page 7, line: 4X10. Mother shows that her family accepted the child and supported her. Transcript 5 page 9, lines 5X5. Mother indicated that some family members were supportive. Transcript 6, page 11, lines 6X5. Some neighbours are supportive in terms of caring and ensuring safety. Transcript 9, page 17 lines 9X7. Mother indicates that neighbours are supportive because they know the fate of children with albinism. Another neighbour is more supportive because she has experienced raising a child with Transcript 9, page 17, lines: 9X8. Some people are supportive. Transcript 10, page 20, lines:10X9. Mother

<p>indicates that only her family support her. Transcript 10, page 20, and lines: 10X11 Mother is scared but she is supported by her mother and strengthened by prayer. Transcript 10, page 21, lines: 10X18. Transcript 6, page 11, lines 6X1. Mother indicated that some family members were supportive while others despised her child by calling her names like “white person. Transcript 6, page 11, lines 6X5. Mother and her child are called pigs by relatives and friend, Mother shows that she encounters financial constrains at times. Transcript 6, page 11, lines: 6X10. Mother heard that albinism is caused by paint found in men. Transcript 7, page 14, lines:7X13.</p> <p>Mother and child are called names like ‘napweri’ and a doll. Transcript 8, page 15, line: 8X6. Some people think mother slept with a white person or a man with albinism. Transcript 8, page 15, line: 8X8. A child has poor sight, mother has financial problems and teacher is supportive. Transcript 8, page 15, lines: 8X10. Mother feels pain and seeks for God’s protection. Transcript 8 page 15, lines:8X11. Mother was worried about how she would protect her child from skin problems because of her previous experience regarding skin problems associated with albinism. Transcript, 9, page 17, lines: 9X1. Mother experienced pain especially being her first child but eventually accepted her child. Transcript 9, page 18, lines: 9X10. Mother shows that her family accepted the child, but the husband and family did not. Transcript 10, page 1, lines: 10X5. The husband’s family think the wife cheated on the husband. Transcript 10, page 19, lines 10X6. Her child has poor eye sight, but the teacher offers support. Transcript 10, page 20, lines: 10X11. Mother is scared but she is supported by her mother and strengthened by prayer. Transcript 10, page 20, lines: 10X18</p>		
<p><b>Formulated meanings</b></p>	<p><b>Theme clusters</b></p>	<p><b>Emergent theme</b></p>
<p>Mother indicates acceptance of her child born with albinism. Transcript 1, page 1 lines 1X1. Mother indicates that she accepted her child with no problems Transcript 3, page 5, line: 3X1. Mother shows that nurses accepted her child. Mother indicates that motherly love helped her to accept the child at once. Transcript 4, page 7, lines: 4X3. Neighbours accept a child with albinism as any normal child. Transcript 4, page 7, line: 4X10. Mother indicates that motherly love helped her to accept the child at once. Transcript 5 page 9, line: 5X2. Mother shows that her family accepted the child and supported her. Transcript 5 page 9, lines 5X5. Mother shows love and acceptance of her child Transcript 7, page 13, lines 7X1. Mother accepts her child just like any normal child Transcript 8, page 15, lines: 8X1, 8X2. Mother shows that her family accepted the child, but the husband and family did not. Transcript 10, page 19, lines: 10X5. Mother perceive a child with albinism just like any human being. Transcript 1 page 1, line 1X13. Mother believes that her child with albinism is just like any human being despite a different appearance. Transcript 8, page 16, lines: 8X13. Mother got some information that people with albinism are also human beings from the radio. Transcript 8. Page 16, lines: 8X16.</p> <p>Transcript 8. Page 16, lines: 8X15. Mother tells her child that he is just like any human being despite a difference in complexion. Transcript 9, page 18, lines: 9X13. Mother tells her child that he is just like any child. Transcript 10, Page 20, lines:10X15. People should not discriminate a child with albinism because of the appearance than a normal child. Transcript, 1 page 2, line 1X17</p> <p>Neighbours accept a child with albinism as any normal child. Transcript 4, page 7, line: 4X10</p> <p>Transcript 4, page 7, line: 4X10. Mother describes her child as any normal child as long as he is cared accordingly. Transcript 4, page 8-line</p>	<p><i>Acceptance</i> <i>Cont’d.</i></p>	<p><b>MOTHERS IMPRESSION OF A CHILD WITH ALBINISM.</b></p>

<p>4X13. Mother is working hard to educate her child so that society should be able to realise that there is potential in a child with albinism just like in any normal child. Transcript 5, page 10, lines 5x10. Mother understand a child with albinism as any normal child 7X2. Mother believes a person with albinism is just like any human being. Transcript 6, page 12, lines:6X12. Malawi Broadcasting radio promote albinism awareness by telling people that people with albinism are human beings. Transcript 6, page 12, lines: 6X15 Mother accepts her child just like any normal child. Transcript 8, page 15, lines: 8X2. Mother tells her child that he is just like any child despite appearance, they have similar body parts Transcript 10, Page 20, lines:10X15</p>		
<p>Mother believes that children with albinism are rarely found and that it could be the first time for midwives to deliver a child with albinism. Transcript 1, Page 1, lines 1X4. albinism is not common considering that nurses are surprised with the appearance of the baby. Transcript 1 page 1-line 1X6. Mother feels that society is not used to children with albinism because they are rarely found. Transcript, 2 pages 1 &amp;4, line 2X6,2X10.</p> <p>Mother believe that some midwives and nurses may be involved in helping mothers kill their children when they are born with albinism Transcript 5, page 9 lines: 5X4 Some neighbours think the hospital supply free sun cream to attract people with albinism so that they can sell or kill them. Transcript 10, page 20, lines: 10X9. People believe that health workers are involved in the stealing and killing of people with albinism. Transcript 10, page 20, lines: 10X10</p>	<p><i>Mothers' perceptions of health workers' attitudes</i></p>	<p><b>MOTHERS' IMPRESSION OF CHILDREN BORN WITH ALBINISM</b></p> <p>(cont'd)</p>
<p>Formulated meanings</p>	<p><b>Cluster themes</b></p>	<p><b>Emerged theme</b></p>
<p>Mother understands that albinism is caused by a problem found in a woman or man. but does not reckon the problem. Transcript 1, page 2, line 1X16. Mother is informed on how to protect her child from sunlight but lack information on the “real cause” of albinism. Transcript 2, page 4-line 2X13 Mother tells her child that she is a white person. Transcript 2, page 3, line, 2X15. Mother understands albinism as something caused by weak genes which fail to development of the top layer skin. Mother understand albinism as a condition caused by mwanamphepo. Transcript 9 page 18, lines: 9X11. Mother understands that albinism has something to do with genes. Mother heard that albinism is caused by paint found in men. Transcript 7, page 14, lines:7X13</p> <p>Transcript 3, page 6, lines:3X13. Mother has information on the cause of albinism from health workers. Transcript 3, page 6 line: 3X14. Mother does not understand clearly the cause of albinism. Transcript 5, page. 10, lines: 5X11. No information regarding albinism was given to the mother after birth of her child by nurses or doctors Transcript 5, page 10, lines 5X12. Health workers did not counsel or explain anything about albinism after birth. Transcript 6, page12, lines: 6X13. Mother shows that midwives are did not give a clear explanation of condition of the child. Transcript 8, page 15, lines: 8X3 Mother indicates that she was not given any information regarding her child by health workers after birth. Transcript 7, page, 13, lines: 7X3. Transcript 9 page 18, lines: 9X11.No information regarding albinism was given to the mother by health workers after birth. Transcript 9, page 18, lines: 9X12. Doctors told the mother that her child had no problems. Transcript 10, page 19, lines 10X3. People lack understanding of the cause of albinism. Transcript 10, page 19, lines: 10X8. Mother is not aware of the cause of albinism</p>	<p><i>Lack of awareness of the physiological causes of albinism</i></p> <p><i>Paucity of information regarding the cause of albinism</i></p>	<p><b>MOTHERS' AWARENESS OF ALBINISM</b></p>

<p>Transcript 10, page 20, lines: 10X12. Health workers regarded albinism as normal. Transcript 10, page 20, lines: 10X14.</p> <p>Mother listened to a story of one person with albinism who was killed from the Malawi Broadcasting cooperation radio. Transcript 7, page 14. Lines:7X16. Mother got some information regarding the safety of people from her community leader.”. Transcript 7, page 14. Lines:7X16</p> <p>. Mother indicates awareness of physical problems associated with children born with albinism. Transcript 1 page 1, lines 1X6. Mother is informed on how to care her child but lack information on the “real cause” of albinism. Transcript 2 Page 4, line 2X14. Transcript 3, page 6, lines:3X13. Mother was educated on sun preventive measures and where to access cream. Transcript 4, page 8, line 4X14. Mother was worried about how she would protect her child from skin problems because of her previous experience regarding skin problems associated with albinism. Transcript, 9, page 17, lines: 9X1. Mother was worried because of her previous experience about skin problems which affect children with albinism. Transcript 9, page 17, lines: 9X2.</p> <p>Inadequate supply of sun cream makes mothers spend a lot of money due to multiple trips to the hospital within a short period of time. Transcript 7, page 14, lines: 7X11. Mother indicate that only her family support the child financially, but the father abandoned him. Transcript 10 page 20, lines: 10X11. Mother experiences financial constraints just to keep her child safe. Transcript 5 page 1, lines: 5X9. Her child has poor eye sight, can’t afford glasses but the teacher offers support. Transcript 8, page 15, lines 8X10. Transcript 10, page 20, lines: 10X11. Mother expresses her concern for spending money on sun cream which she could get for free if she was informed. Transcript 9, page 17, lines: 9X9</p>	<p><i>Role of local radio broadcasts</i></p> <p><i>Awareness of unavailability and expense of sun productive products</i></p>	
<p>Mother expresses the feeling of pain Transcript 6, page 11, lines: 6X11. Mother felt disappointed after giving birth to a child with albinism but got assured encouraged and supported by her mother. Mother felt pain for giving birth to a child with albinism but later accepted. Transcript 6, page 11, lines 6X1</p>	<p><i>Feeling of pain, anger and shame</i></p>	<p><b>PSYCHOSOCIAL EFFECTS OF ALBINISM</b></p>
<p>Refusing to go to school leads to unemployment in future. Transcript 2 page 4, lines 2X11. Mother thinks that her daughter struggles to get a job of her scope due to her condition. Transcript 6, page 11, lines: 6X6.</p>	<p><i>Implications on employment.</i></p>	<p><b>PSYCHO..</b> Cont.</p>

## APPENDIX 13: DEFINING AND NAMING THEMES

### SUB-THEMES OF FIRST THEME relating to MOTHERS' EXPERIENCES of raising children born with albinism

#### *Stigmatisation, harm and discrimination*

- Children with albinism deserve to be killed immediately after birth 5X4, 10X9
- Spitting out or touching hair after meeting a person with albinism. 5X7
- Regarding albinism as a contagious disease. 5X8
- A child with albinism is a doll. 8X6.
- A person or a Child with albinism looks like pig/pork, 6X10.
- A person with albinism is not a human 6X7, no potential 6X11
- Albinism is caused by 'mwanamphepo' (taboo which entails that if a pregnant mother develops skin disease, will give birth to a child with albinism 9X13
- Private parts of people with albinism are a source of wealth 10X7,
- People with albinism smell like sun 2X5
- Albinism brings calamity to the society 2X5.
- Child almost disappeared (life testimony).

#### *Acceptance by family members*

- Mother's family accepted the child and supported 5X5, 6X5
- Some people love and accept her 9X8
- Mother supportive 10X18
- Some neighbours understand the fate of children with albinism 9X7
- Teachers are supportive at school 10X11, 8X10
- child with albinism is just like any human being (all participants)10/10
- No discrimination of a child with albinism because of the appearance
- There is potential in a child with albinism just like in any normal child 5X10
- Gift from God. 4X1
- God cannot create a bad thing. 2X2
- They deserve love. 1X17
- Children with albinism are rarely found 2X10

#### *Rejection from family members and husbands*

- Abuse from husband and his family members, separated for six months 10X5
- Mother divorced 3X11
- Only her family support the child financially, but the father abandoned him 10X7, 10X11
- Mother isolates herself from neighbours/friends for fear of evil advice 10X9
- Husband plainly said he doesn't want a child with albinism and asked mother to choose between a child and her marriage. 10X7
- some relatives call her child "Napweri "meaning dry pigeon peas" 6X8
- Some relatives are disappointed because they have no history of albinism in the family.7X6, 5X5
- Being accused of cheating with another man. 7X6, 5X5, 10X5
- Disappointment after giving birth to a child with albinism 2X1
- Child fears to date a normal man due to loss of trust in people 6X6
- Mother lacks proper sleep due to *fear*

**SUB-THEMES OF SECOND THEME relating to MOTHERS' PERCEPTIONS of their experiences of raising children born with albinism**

***Mothers' perception of Health workers' attitudes***

- midwives and nurses may be involved in helping mothers kill their children when they are born with albinism 5X4
- hospital supplies free sun cream to attract people with albinism so that they can sell or kill them, 10X9, people believe that health workers are involved in the stealing and killing of people with albinism 10X9
- children with albinism are rarely found and that it could be the first time for some midwives to deliver a child with albinism 1X4
- no parental involvement in the decision regarding welfare of a baby. 5X3

**SUB-THEMES OF THIRD THEME relating to MOTHERS' AWARENESS OF ALBINISM**

***Awareness of albinism and physical problems associated with albinism.***

- Educated on sun preventive measures 4X14
- Awareness of where to access cream. 01X-010X
- Previous experience of skin problems associated with children with albinism. 9X1
- Awareness of poor sight. 9X1, 1X6
- Awareness of safety precautions from community leader and "Radio Malawi" 7X16
- Awareness of selling and killing of people with albinism. 8X13 (life experience testimonies given). 10X7, 9X9, 7X16, 5X14, 5X15, 4X11, 1X11, 5X4, 6x5

***Paucity of information on the cause of albinism***

- Albinism is caused by a problem found in a woman or man. 1X16
- Albinism is caused by weak genes which fail to develop of the top layer skin. 3X13
- No information regarding the cause of albinism 5X12, 6X13, 9X13, 6X13, 10X13, 2X13
- No clear understanding, the cause of albinism. 5X11, 7X3
- Albinism is caused by some paint found in the abdomen 7X13
- Doctors told the mother that her child had no problems 10X3

Albinism is caused by mwanamphepo [translate for examiners] 9X13

***Unavailability and expense of sun protective products***

- Inadequate supply of sun cream makes her spend a lot of money due to multiple trips to the hospital within a short period of time. 7X11
- Mother expresses her concern for spending money on sun cream which she could get for free if she was informed 9X11
- Visual challenges

**SUB-THEMES OF FOURTH THEME: PSYCHOSOCIAL EFFECTS OF ALBINISM**

***Feeling of Loss of self-esteem. 2X2***

***Pain, anger, shame and emotional trauma. 10X7***

***Implication on employment***

Financial support of the child only from mother's side, but the father abandoned him. 10X11

- Refuses to go to school

- Struggles to get a job of her scope.

## APPENDIX 14: Consolidated criteria for reporting qualitative studies (COREQ)

### Interviews & Focus groups

Consolidated criteria for reporting qualitative studies (COREQ): 32-item checklist

No.	Item	Guide questions/description	Page	
<b>Domain 1: Research team and reflexivity</b>				
Personal Characteristics				
1.	Interviewer/facilitator	Which author/s conducted the interview or focus group?	Title page	Naomi Likumbo
2.	Credentials	What were the researcher's credentials? <i>E.g. PhD, MD</i>	Title page	Masters of nursing science student
3.	Occupation	What was their occupation at the time of the study?	Title Page	Nursing/Midwife/ child nurse specialist
4.	Gender	Was the researcher male or female?	N/A	Female
5.	Experience and training	What experience or training did the researcher have?	16	PGD Child nurse, BSc. education and management, <u>principles of genetic counselling.</u>
Relationship with participants				
6.	Relationship established	Was a relationship established prior to study commencement?	14	The researcher had no prior relationship with any participants.
7.	Participant knowledge of the interviewer	What did the participants know about the researcher? <i>e.g. personal goals, reasons for doing the research</i>	(APP.2) 18 Appendix 2 and 4	Study was for fulfilment of master's degree; results may help to educate nursing and health profession understand albinism. At broader level may educate the community.
8.	Interviewer characteristics	What characteristics were reported about the interviewer/facilitator? <i>e.g. Bias, assumptions, reasons and interests in the research topic</i>	15, 49	The initial plan was to use back translators who were not aware of the topic, but one of the forward translators was used twice because one of the backward translators previously identified, lost a brother in a car accident.
<b>Domain 2: study design</b>				
Theoretical framework				
9.	Methodological orientation and Theory	What methodological orientation was stated to underpin the study? <i>e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis</i>	13-22	Descriptive qualitative
Participant selection				
10.	Sampling	How were participants selected? <i>e.g. purposive, convenience, consecutive, snowball</i>	13-14	Purposive sampling

No.	Item	Guide questions/description	Page	
11.	Method of approach	How were participants approached? e.g. <i>face-to-face, telephone, mail, email</i>	16	Face to face Interviews.
12.	Sample size	How many participants were in the study?	14	Ten participants in total.
13.	Non-participation	How many people refused to participate or dropped out? Reasons?	N/A	none
<b>Setting</b>				
14.	Setting of data collection	Where was the data collected? e.g. <i>home, clinic, workplace</i>	13	Queen Elizabeth Central Hospital Dermatology clinic Blantyre, Malawi.
15.	Presence of non-participants	Was anyone else present besides the participants and researchers?	20	One nurse to help with drinks and keep company of children during the interviews but not in the interview room.
16.	Description of sample	What are the important characteristics of the sample? e.g. <i>demographic data, date</i>	24	Participants were mothers of children with albinism of different ages over the age of 18. Some were married, some divorced and some single. Only 2 mothers were white in complexion, the rest were black.
<b>Data collection</b>				
17.	Interview guide	Were questions, prompts, guides provided by the authors? Was its pilot tested?	16, appendix 4	Not pilot tested but the Interview guide was guided by literature and study objectives.
18.	Repeat interviews	Were repeat interviews carried out? If yes, how many?	20	Member checking telephonically.
19.	Audio/visual recording	Did the research use audio or visual recording to collect the data?	16	Audio recording.
20.	Field notes	Were field notes made during and/or after the interview or focus group?	16	During and after the interviews
21.	Duration	What was the duration of the interviews or focus group?	16	30-45minutes each.
22.	Data saturation	Was data saturation discussed?	14	Yes.
23.	Transcripts returned	Were transcripts returned to participants for comment and/or correction?	17	Participants were contacted by phone as per choice to verify the results.
<b>Domain 3: analysis and findings</b>				
<b>Data analysis</b>			17-18	Thematic analysis
24.	Number of data coders	How many data coders coded the data?		
25.	Description of the coding tree	Did authors provide a description of the coding tree?	17	Hierarchical coding
26.	Derivation of themes	Were themes identified in advance or derived from the data?	23-40	Themes emerged from data.

No.	Item	Guide questions/description	Page	
27.	Software	What software, if applicable, was used to manage the data?	17	Data was analysed manually.
28.	Participant checking	Did participants provide feedback on the findings?	20 and 26	Yes, all agreed with the findings.
Reporting				
29.	Quotations presented	Were participant quotations presented to illustrate the themes / findings? Was each quotation identified? e.g. <i>participant number</i>	23-39	Yes, quotations were presented and each quotation was identified with a code
30.	Data and findings consistent	Was there consistency between the data presented and the findings?	23-39	Yes.
31.	Clarity of major themes	Were major themes clearly presented in the findings?	23- 39	yes
32.	Clarity of minor themes	Is there a description of diverse cases or discussion of minor themes?	41-48	Weaved to together with literature

Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Into J Qual Health Care.* 2007;19(6):349-357.

## APPENDIX 15: Standards for Reporting Qualitative Research (SRQR)

### Standards for Reporting Qualitative Research (SRQR)<sup>a</sup>

No.	Topic	Item	Page	
	<b>Title and abstract</b>			
S1	Title	Concise description of the nature and topic of the study Identifying the study as qualitative or indicating the approach (e.g., ethnography, grounded theory) or data collection methods (e.g., interview, focus group) is recommended	Title page and 13	Experiences and perceptions of mothers of children living with albinism in Malawi: A qualitative descriptive study. Data collected using Semi structured interview
S2	Abstract	Summary of key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results, and conclusions	Vii	Done
	<b>Introduction</b>		1	
S3	Problem formulation	Description and significance of the problem/phenomenon studied; review of relevant theory and empirical work; problem statement	2	explained
S4	Purpose or research question	se of the study and specific objectives or questions	2	Described
	<b>Methods</b>			
S5	Qualitative approach and research paradigm	Qualitative approach (e.g., ethnography, grounded theory, case study, phenomenology, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g., post positivist, constructivist/ interpretivist) is also recommended; rationale	13	Descriptive qualitative
S6	Researcher characteristics and reflexivity	Researchers' characteristics that may influence the research, including personal attributes, qualifications/experience, relationship with participants, assumptions, and/or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results, and/or transferability	14	Nurse/ Malawian, familiar with social problems affecting people with albinism.
S7	Context	Setting/site and salient contextual factors; rationale <sup>b</sup>	13	Described
S8	Sampling strategy	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g., sampling saturation); rationale <sup>b</sup>	13-14	Purposive
S9	Ethical issues pertaining to human subjects	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	20-22	Done

No.	Topic	Item	Page	
S10	Data collection methods	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources/methods, and modification of procedures in response to evolving study findings; rationale	14-15	Provided. All participants volunteered to sign consent form on the same day after explanation.
S11	Data collection instruments and technologies	Description of instruments (e.g., interview guides, questionnaires) and devices (e.g., audio recorders) used for data collection; if/how the instrument(s) changed over the course of the study	15- 16	Done
S12	Units of study	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	14	Described
S13	Data processing	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymization/deidentification of excerpts	17	Described
S14	Data analysis	Process by which inferences, themes, etc., were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	17-18	Thematic analysis
S15	Techniques to enhance trustworthiness	Techniques to enhance trustworthiness and credibility of data analysis (e.g., member checking, audit trail, triangulation); rationale	19-20	Described
	<b>Results/findings</b>			
S16	Synthesis and interpretation	Main findings (e.g., interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	37-38	Interpretations and themes done
S17	Links to empirical data	Evidence (e.g., quotes, field notes, text excerpts, photographs) to substantiate analytic findings	23 -39	Text excerpts
S18	Integration with prior work, implications, transferability, and contribution(s) to the field	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application/ generalizability; identification of unique contribution(s) to scholarship in a discipline or field	41-48	Done
S19	Limitations	Trustworthiness and limitations of findings	48	Described
S20	Conflicts of interest	Potential sources of influence or perceived influence on study conduct and conclusions; how these were managed	15-16	No conflict of interest
S21	Funding	Sources of funding and other support; role of funders in data collection, interpretation, and reporting	V	Self- funded- study.

The authors created the SRQR by searching the literature to identify guidelines, reporting standards, and critical appraisal criteria for qualitative research; reviewing the reference lists of retrieved sources; and contacting experts to gain feedback. The SRQR aims to improve the transparency of all aspects of qualitative research by providing clear standards for reporting qualitative research.

The rationale should briefly discuss the justification for choosing that theory, approach, method, or technique rather than other options available, the assumptions and limitations implicit in those choices, and how those choices influence study conclusions and transferability. As appropriate, the rationale for several items might be discussed together.