Declaration

I declare that this research project entitled “Guidelines for nurses to support primary caregivers of People Living with HIV/AIDS in palliative care in Malawi” is my own work and has not been submitted for any degree or examination in any other university. All the sources that I have used have been acknowledged by means of complete references.

Researchers Name: Esmie Mkwinda

Researchers Signature:
DEDICATION

DEDICATED TO MY MUM AND DAD,
MY HUSBAND AND
MY CHILDREN, MARTHA, OLIVE AND PAUL AND JUNIOR,
WHO WITH LOVE AND SUPPORT
ASSISTED ME TO FULFILL THIS DREAM
I thank God almighty for giving me life, good health and wisdom throughout the journey of this thesis. Thank you Lord for the miracles you’ve shown me throughout the study period. My sincere gratitude goes to the following people who contributed to the success of this study:

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ABSTRACT

Lack of support for primary caregivers of HIV/AIDS patients from nurses affects the quality of life for PLWHA. As the current management of HIV/AIDS with antiretroviral therapy (ART) has made HIV/AIDS patients to live long and HIV a chronic condition, patients are now cared for by primary caregivers at home and supporting them in their role would ensure that proper care is provided hence improvement of quality of lives. Nurses care for HIV/AIDS patients in the clinics and hospitals but there is need to involve primary caregivers who care for these patients at home in order for continuity of care to be achieved. This study was aimed at development of guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi by meeting the following objectives:

- To explore and describe the needs of primary caregivers in relation to the care they give to HIV/AIDS patients and support they get from palliative care nurses;
- To explore and describe the palliative care needs of HIV/AIDS patients in relation to care received from primary caregivers;
- To explore and describe the needs of palliative care nurses in relation to supporting primary caregivers of HIV/AIDS patients;
- To synthesize existing evidence regarding ‘support’ to primary caregivers of HIV/AIDS patients in palliative care through an integrative literature review; and
- To develop, describe and evaluate guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care in Malawi.

The study was conducted at three palliative care sites in Malawi namely: Ndi Moyo palliative care clinic in Salima district, Kamuzu Central Hospital palliative care clinic and Nkhoma hospital palliative care clinic in Lilongwe district respectively. A qualitative research design utilizing the descriptive, explorative and contextual research approach was used in this study. Data was collected using individual interviews and focus group discussions with fifty one (51) participants. Individual interviews were conducted with eighteen (18) HIV/AIDS patients and
eighteen (18) primary caregivers and focus group discussions were conducted with fifteen (15) palliative care nurses from three palliative care sites.

Concurrent analysis of data was done manually using Tesch steps and also with Nvivo software package version 10 by the researcher and independent coder and consensus was reached on categories and subcategories that emerged from the data. Findings from palliative care nurses revealed need for training, resources, support and need for guidelines. Result findings from primary caregivers indicated need for training, resources and support in their role and findings from HIV/AIDS patients revealed need for physical care, quality health care services, knowledge, resources and need for support. This was followed by synthesizing existing evidence regarding support to primary caregivers in palliative care through an integrative literature review for better understanding of the concept “support”.

Results from the study findings and literature assisted in development of guidelines following a modified, adapted and integrated Evidence-Based Guidelines Development (EBGD) and National Institute for Health and Clinical Excellence (NICE) process. The guidelines were drafted by the researcher based on the study findings and literature and were refined by thirteen experts. The final guidelines included five key aspects which are as follows: ethics and caring; resources management; holistic approach in palliative care; improving knowledge in palliative care; record keeping, monitoring, evaluation and reporting. Based on the objectives of the study guidelines for nurses to support primary caregivers of HIV/AIDS patients in palliative care were described with actions to be implemented by the palliative care nurses.

The study recommended that palliative care nurses be supported to improve their skills and knowledge to provide proper support to primary caregivers for quality patient care to be achieved. In addition, it was recommended that primary caregivers be supported through training, information, visitations and constant contact with nurses for quality care to be provided to HIV/AIDS patients. Furthermore, the study recommended that follow-up research be conducted to evaluate the guidelines; education and training curriculum of nurses to contain palliative care at all levels with complex interrelation between support of primary caregivers and palliative care nurses to achieve quality patient care.
Key words:
Palliative care; primary caregivers, HIV/AIDS patient, Integrative literature review, support,
TABLE OF CONTENTS

DECLARATION i
DEDICATION ii
ACKNOWLEDGEMENT iii
ABSTRACT v
TABLE OF CONTENTS vii
LIST OF ANNEXURES xiii
LIST OF TABLES xiv
LIST OF FIGURES xv
LIST OF ABBREVIATIONS xvi

CHAPTER 1: ORIENTATION TO THE RESEARCH STUDY 1
1.1 INTRODUCTION AND BACKGROUND 1
1.2 PROBLEM STATEMENT 5
1.3 RESEARCH QUESTIONS 6
1.4 RESEARCH PURPOSE 6
1.5 OBJECTIVES OF THE STUDY 6
1.6 MOTIVATION OF THE STUDY 7
1.7 SIGNIFICANCE OF THE STUDY 8
1.8 DEFINITION OF CONCEPTS 10
1.9 RESEARCH DESIGN AND METHODOLOGY 11
1.10 ORGANIZATION AND OUTLINE OF THE THESIS 11
1.11 SUMMARY 12

CHAPTER 2: RESEARCH DESIGN AND METHODOLOGY 13
2.1 INTRODUCTION 13
2.2 RESEARCH DESIGN AND METHODS 14
   2.2.1 A qualitative design 14
   2.2.2 A descriptive approach 16
   2.2.3 An explorative approach 17
2.2.4 Contextuality

2.3 THE STUDY SETTING

2.4 POPULATION

2.5 SAMPLING
   2.5.1 Sample and sampling process
   2.5.2 Sample size
   2.5.3 Recruitment process

2.6 THE ROLE OF THE RESEARCHER IN THE PROCESS OF
   DATA COLLECTION
   2.6.1 Gaining entry
   2.6.2 Establishing rapport and developing a trusting relationship
   2.6.3 Interviewing techniques used by the researcher

2.7 DATA COLLECTION
   2.7.1 Pilot study
   2.7.2 Data collection strategies
      2.7.2.1 Semi-structured in-depth interviews
      2.7.2.2 Planning and conducting individual in-depth interviews
      2.7.2.3 Focus group discussion
      2.7.2.4 Planning and conducting the focus group discussion

2.8 DATA ANALYSIS
   2.8.1 Transcribing of the interviews
   2.8.2 Tesch’s steps of data analysis
   2.8.3 Data analysis using NVivo software package

2.9 REASONING STRATEGIES OF THE RESEARCHER
   2.9.1 Analysis
   2.9.2 Synthesis
   2.9.3 Inductive
   2.9.4 Deductive

2.10 TRUSTWORTHINESS
   2.10.1 Credibility
   2.10.2 Dependability
CHAPTER 5: PHASE TWO
INTEGRATIVE LITERATURE REVIEW OF SUPPORT TO
PRIMARY CAREGIVERS OF HIV/AIDS PATIENTS IN PALLIATIVE CARE
5.1 INTRODUCTION
5.2 LITERATURE SEARCH PROCESS
5.3 RELEVANT ARTICLES
5.4 FINDINGS
5.5 THEMES ON SUPPORT OF PRIMARY CAREGIVERS
5.5.1 Theme one: Caregivers self description of support
5.5.2 Theme two: Impact of caring role on caregivers
5.5.3 Theme three: Support needs of caregivers
5.5.4 Theme four: Interventions for improving support to caregivers
5.6 SUMMARY OF THE SELECTED ARTICLES
5.7 SUMMARY

CHAPTER 6: PHASE THREE
DEVELOPMENT AND DESCRIPTION OF GUIDELINES FOR
NURSES TO SUPPORT PRIMARY CAREGIVERS OF HIV/AIDS PATIENTS IN
PALLIATIVE CARE IN MALAWI
6.1 INTRODUCTION
6.1.1 Step one of the EBGD and NICE process
6.1.1.1 Selection of experts/stakeholders
6.1.1.2 Review of baseline data as a background to guidelines development
6.1.2 Step two of the EBGD and NICE process
6.1.2.1 Exploring the current goals
6.1.2.2 Formulation of the clinical question
6.1.2.3 Consultation draft of the guidelines
6.1.2.4 Management of the consultation with experts
6.1.3 Step three of the EBGD and NICE process
LIST OF ANNEXURES

Appendix A: Map of Malawi 193
Appendix B: Ethical Clearance certificates 194
Appendix C: Institutional endorsement certificate 195
Appendix D (a): Request for permission from ministry of Health 196
Appendix D (b): Approval from Ministry of Health 198
Appendix E: Approval from Lilongwe District Health Officer 199
Appendix F: Approval from Salima District Health Officer 201
Appendix G: Approval from Mzimba District Health Officer 202
Appendix H: Approval from Kamuzu Central Hospital 204
Appendix I: Approval from Ndimoyo Palliative care centre 206
Appendix J: Approval from Nkhoma Hospital 208
Appendix K (a): Information about the study (English) 210
Appendix K (b): Information about the study (Chichewa) 212
Appendix L: English consent form 214
Appendix M: Chichewa consent form 215
Appendix N (a): Data collection tool (HIV/AIDS patients) (English) 218
Appendix N (b): Data collection tool (HIV/AIDS patients) (Chichewa) 219
Appendix O (a): Data collection tool (primary caregivers) (English) 221
Appendix O (b): Data collection tool (primary caregivers) (Chichewa) 222
Appendix P: Data collection tool for palliative care nurses 223
Appendix Q: Letter for the language editor 225
Appendix R: Letter having guidelines evaluation guide 226
Appendix S: Draft of guidelines 228
Appendix T: Guidelines evaluation guide 241
**LIST OF TABLES**

Table 2.1: Population size from three study sites 20
Table 2.2: Sample size from the three study sites 22
Table 3.1: Baseline characteristics of palliative care nurses 48
Table 3.2: Themes, categories and subcategories for palliative care nurses 49
Table 3.3: Baseline characteristics of primary caregivers 66
Table 3.4: Themes, categories and subcategories of primary caregivers 67
Table 3.5: Baseline characteristics of PLWHA 78
Table 3.6: Themes, categories and subcategories for PLWHA 79
Table 5.1: Search terms used in electronic database 112
Table 5.2: Inclusion and exclusion criteria of articles being searched 112
Table 5.3: Summary of the researches done on support of primary caregivers 113
Table 6.1: Descriptive information of experts 122
Table 6.2: BMI according to WHO guide 149
Table 6.3: Six domains and application of guidelines for quality of practice 159
LIST OF FIGURES

Figure 2.1: Schematic representation of the research study .............................................. 13
Figure 6.1: Evidence-Based Guidelines Development and National Institute for Health and Clinical Excellence Guide ................................................................. 120
Figure 6.2: Key aspects of the guidelines ........................................................................... 132
Figure 6.3: Pain assessment scale ....................................................................................... 153
Figure 6.4: WHO analgesic ladder ...................................................................................... 154
List of abbreviations

AIDS Acquired Immunodeficiency Syndrome
AGREE Appraisal of Guidelines for Research and Evaluation
ART Antiretroviral Therapy
APCA African Palliative Care Association
BMI Body Mass Index
CBO Community Based Organizations
CHAM Christian Health Association of Malawi
CHBC Community Home-Based Care
CPD Continuous Professional Development
KCH Kamuzu Central Hospital
DHO District Health Officers
NAC National AIDS Commission
NGO Non-governmental Organizations
HIV Human Immunodeficiency Disease
HBC Home-Based Care
PACAM Palliative Care Association of Malawi
PLWHA People Living With HIV/AIDS
PMTCT Prevention of mother-to-child transmission
PHC Primary Health Care
MoH Ministry of Health
MREC Medunsa Research Ethics Committee
NHRC National Health Sciences Research Committee
NMCM Nurses and Midwives Council of Malawi
NSO National Statistical Office
USAID United States Agency for International Development
VIA Visual inspection using Acetic acid
WHO World Health Organization
WMA World Medical Association’s
UNAIDS The Joint United Nations programme on HIV/AIDS
UNICEF United Children’s Fund
NICE  National Institute for Health and Clinical Excellence
EBGD  Evidence-Based Guidelines Development