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BEST PRACTICE GUIDELINES ON END-OF-LIFE CARE FOR INTENSIVE CARE NURSES IN PUBLIC SECTOR INTENSIVE CARE UNITS IN GAUTENG PROVINCE

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A thesis submitted to the

Faculty of Health Sciences, University of the Witwatersrand, Johannesburg,

in fulfilment of the requirements for the degree of Doctor of Philosophy

Johannesburg, 2013

DECLARATION

I, Kisorio Leah Chepkoech, declare that this thesis is my own work. It is being submitted for the degree of Doctor of philosophy at the University of the Witwatersrand, Johannesburg. It has not been submitted before for any degree or examination at this or any other university.

Signature …….

……day of …… 2013

University of the Witwatersrand Human Research Committee protocol Number: **M10525**

University of Pretoria Human Research Ethics Committee protocol number: **209/2011**

DEDICATION

Thank you God, you have done it for me again. Because you live, I can face tomorrow...

ACKNOWLEDGEMENTS

Without continuous support of many people, this journey would have been difficult and depressing. I wish to acknowledge and thank the following people for their support and encouragement:

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ABSTRACT

The management of critically ill patients at end-of-life (EOL) is concerned with shifting the focus of care from curing disease to maximizing comfort and ensuring the needs of the patient and family (Carey & Cosgrove 2006). Despite the availability of a wide range of EOL care studies, there appears to be inadequate knowledge of how best intensive care nurses can cope and provide ethical, quality, humane, holistic and comfort care for the dying patients including these patients' family members in the ICU.

Purpose: To develop best practice guidelines for end-of-life care for intensive care nurses in adult intensive care units at three tertiary level III hospitals in Gauteng province.

Objectives: 1) To search and analyze for quality research discourse on EOL care by means of a systematic review, 2) To search for evidence on EOL care through interviews with family members, interviews with critically ill patients and focus group discussions with intensive care nurses. 3) To develop best practice guidelines for intensive care nurses on EOL care. 4) To verify the tentative best practice guidelines using an Appraisal of Guidelines Research and Evaluation (AGREE) II instrument.

Design: Both quantitative and qualitative approaches were used to achieve the aim of the study. Systematic review, semi structured interviews and focus group discussions were utilized during data collection in the various steps of the study. During data analysis, meta-synthesis was utilized for systematic review; Tesch's (1992) eight steps of analysis were used for semi structured interviews whereas the long-table approach was used to analyze transcripts from focus groups. The process of guideline development was divided into three stages: **Stage I** involved the search for quality research evidence on EOL care (this was conducted in 4 steps: In step 1, a systematic review of both qualitative and quantitative articles on EOL care was conducted yielding 23 articles, step 2 included individual interviews with 17 purposively selected family members, step 3 involved individual interviews with 16 purposively selected critically ill patients whereas step 4 included three focus group discussions with 24 purposively selected intensive care nurses). **Stage II** involved development of best practice guidelines in form of recommendations by means of synthesising and integrating conclusions from stage I. **stage III** involved verification of the guidelines by four purposively selected verifiers using the AGREE II instrument.

Findings: The main findings obtained from the four steps in stage I of the study were as follows: step 1) the findings from systematic review were grouped as factors that enable or

complicate EOL care, patients'/family members'/nurses' experiences of EOL care and decision making processes at EOL. Step 2) Five major themes emerged from the experiences of family members on EOL care. These included: "most of the time we are in darkness", "emotional support", "involvement", "you feel you should see her face more often" and "spiritual support". Step 3) Five major themes were identified from the experiences of critically ill patients on comfort care and they included: "being in someone's shoes", "communication", "trust", "presence" and "religion and spirituality". Step 4) Focus group discussion with the intensive care nurses led to five major themes including: "difficulties we get", "discussion and decision making", "support for patients", support for families" and support for nurses. Conclusions drawn from stage I provided evidence for the development of best practice guidelines. Based on the conclusions drawn, guidelines developed were divided into three categories related to: communication, caring and negative aspects impacting on EOL care. The tentative guidelines were verified by a panel of four experts. The verifiers' feedback, recommendations, criticisms and suggestions were analysed and incorporated into the guidelines.

Conclusions: Guidelines were developed to inform nursing practice, nursing management and nursing education. Communication recommendations focused on how to effectively communicate as a health care team as well as instituting communication strategies in dealing with dying patients and their families. Caring recommendations were intended to promote quality care for patients and families at EOL and more so, the care needed by nurses in order for them to continue rendering holistic nursing care. Negative factors impacting on EOL care reflected on what need to be improved so as to ensure quality EOL care. In general, the guidelines were rated to be of high quality and were recommended for use by the verifiers.

TABLE OF CONTENTS

		Page
DECLARATION		ii
DEDICATION		iii
ACKNOWLEDGEMENTS		iv
ABSTRACT		v
TABLE OF CONTENTS		vii
LIST OF FIGURES		xvi
LIST OF TABLES		xvii

CHAPTER 1: OVERVIEW OF THE STUDY

1.1	INTRODUCTION	1
1.2	BACKGROUND TO THE STUDY	1
1.3	PROBLEM STATEMENT	4
1.4	PURPOSE OF THE STUDY	5
1.5	RESEARCH OBJECTIVES	5
1.6	ARGUMENT AND RATIONALE FOR THE STUDY	5
1.7	PARADIGMATIC PERSPECTIVE	6
1.7.1	Meta-theoretical Assumptions	7
1.7.2	Theoretical Assumptions	9
1.7.2.1	Definition of terms for the purpose of this research	10
1.7.3	Methodological Assumptions	11
1.8	RESEARCH DESIGN AND METHOD	13
1.8.1	Overview of research design and method	13
1.8.2	Validity and reliability	16
1.8.3	Ethical considerations	16
1.9	PLAN OF THE STUDY	17
1.10	SUMMARY	17

CHAPTER 2: RESEARCH DESIGN AND METHODS

2.1	INTRODUCTION	18
2.2	RESEARCH DESIGN AND METHODS	20
2.2.1	Stage I**:** search for quality research evidence	20
2.2.1.1	Step 1: systematic review	20
2.2.1.2	Step 2, 3 and 4: Experiences of end of life care	20
2.2.2	Stage II: Development of best practice guidelines on end-of-life care	21
2.2.3	Stage III: Verification of best practice guidelines on end-of-life care	21
2.3	RESEARCH SETTING	22
2.4	RESEARCHER'S A PRIORI VIEW OF THE WORLD (STEPS 2, 3 AND 4)	22
2.5	MEASURES TO ENSURE TRUSTWORTHINESS APPLICABLE TO STEP 2, 3 AND 4	23
2.6	ETHICAL CONSIDERATIONS	26
2.7	SUMMARY	27

CHAPTER 3A: SYSTEMATIC REVIEW

3A.1	INTRODUCTION	28
3A.2	RESEARCH DESIGN	29
3A.3	RESEARCH METHODS	29
3A.3.1	Target population	29
3A.3.2	Sampling and sample	29
3A.3.3	Data collection procedure	29
3A.3.4	Question formulation	30
3A.3.5	Conducting literature search and data extraction	30
3A.3.6	Appraisal of retrieved literature	31
3A.3.6.1	Appraisal of Quantitative studies	32
3A.3.6.2	Appraisal of Qualitative studies	32
3A.3.7	Data synthesis	32
3A.3.8	Validity and reliability	33
3A.4	SELECTION OF INCLUDED STUDIES	33
3A.5	LIST OF INCLUDED STUDIES IN THE FINAL REVIEW	36

3A.6	METHODOLOGICAL QUALITY ASSESSMENT OF THE SELECTED STUDIES	38
3A.7	CHARACTERISTICS OF INCLUDED STUDIES	41
3A.8	RESULTS OF INCLUDED STUDIES	41
3A.8.1	Presentation of the results of Qualitative studies (n=11)	46
3A.8.2	Presentation of the results of Quantitative studies (n=12)	51
3A.9	DISCUSSION	57
3A.9.1	Factors that enable or complicate end-of-life care	58
3A.9.2	Experiences, attitudes, beliefs, feelings and perceptions of end-of-life care	59
3A.9.3	Discussion and decision making processes	61
3A.10	SUMMARY	63

CHAPTER 3B: EXPERIENCES OF FAMILY MEMBERS ON END OF LIFE CARE

3B.1	INTRODUCTION	64
3B.2	RESEARCH DESIGN	65
3B.3	RESEARCH METHODS	65
3B.3.1	Target population	65
3B.3.2	Sampling and sample	65
3B.3.3	Data collection procedure	66
3B.3.4	Data analysis	69
3B.3.4.1	Transcription of data	70
3B.3.4.2	Steps of data analysis	70
3B.3.5	Pilot study	71
3B.4	BIOGRAPHIC INFORMATION OF THE FAMILY PARTICIPANTS	71
3B.5	FINDINGS AND DISCUSSION	72
3B.6	“MOST OF THE TIME WE ARE IN DARKNESS”	73
3B.6.1	“Fetching information bit by bit”	77
3B.6.2	Progress report	80
3B.6.3	Confusion about the information	81
3B.6.4	“Digging holes slowly in our hearts”	83
3B.7	EMOTIONAL SUPPORT	85

3B.7.1	Hope for recovery	87
3B.7.2	Comfort measures	89
3B.7.3	Nurses' hospitality	92
3B.7.4	Empathy/compassion	93
3B.7.5	Nurses' presence	95
3B.8	INVOLVEMENT	97
3B.8.1	Involvement in decision making process	97
3B.8.2	Involvement in direct patient care	100
3B.9	"YOU FEEL YOU SHOULD SEE HER FACE MORE OFTEN"	103
3B.9.1	"You go home and you are just thinking"	103
3B.9.2	Being present till death	107
3B.10	SPIRITUAL SUPPORT	110
3B.10.1	Prayers to the patient	111
3B.10.2	Religious leaders	113
3B.11	CONCLUSION OF THE FINDINGS	114
3B.12	SUMMARY	117

CHAPTER 3C: EXPERIENCES OF CRITICALLY ILL PATIENTS ON COMFORT CARE

3C.1	INTRODUCTION	118
3C.2	RESEARCH DESIGN	119
3C.3	RESEARCH METHOD	119
3C.3.1	Target population	119
3C.3.2	Sampling and sample	120
3C.3.3	Data collection procedure	120
3C.3.4	Data analysis	123
3C.3.5	Pilot study	125
3C.4	DEMOGRAPHIC INFORMATION OF THE PATIENT PARTICIPANTS	125
3C.5	FINDINGS AND DISCUSSION	126
3C.6	"BEING IN SOMEONE'S SHOES"	127
3C.6.1	Sense of compassion	128

3C.6.2	Reassurance	130
3C.6.3	Respect of privacy	132
3C.6.4	Existence of pain	133
3C.6.5	"Lying just like a parcel"	135
3C.6.6	Disturbing noises	137
3C.6.7	Constant anxiety	138
3C.7	COMMUNICATION	140
3C.7.1	Explanation of interventions	140
3C.7.2	"Dealt with like a specimen"	142
3C.8	TRUST	145
3C.8.1	Trust in them	145
3C.9	PRESENCE	147
3C.9.1	Nurses' presence	147
3C.9.2	Family presence	149
3C.9.3	"You don't want your family to know"	153
3C.10	RELIGION AND SPIRITUALITY	155
3C.10.1	Personal prayers	155
3C.10.2	Prayers from nurses	156
3C.10.3	Prayers from religious leaders	157
3C.11	CONCLUSION OF THE FINDINGS	159
3C.12	SUMMARY	162

CHAPTER 3D: INTENSIVE CARE NURSES' EXPERIECES OF END-OF-LIFE CARE

3D.1	INTRODUCTION	163
3D.2	RESEARCH DESIGN	164
3D.3	RESEARCH METHOD	164
3D.3.1	Target population	164
3D.3.2	Sample and sampling method	164
3D.3.3	Data collection procedure	165
3D.3.4	Data analysis	167
3D.3.5	Pilot study	169

3D.4	THE PROFILE OF THE NURSE PARTICIPANTS	169
3D.5	FINDINGS AND DISCUSSION	170
3D.6	"DIFFICULTIES WE GET"	171
3D.6.1	Psychological and emotional stress	172
3D.6.2	"Tell or not to tell"	173
3D.6.3	"She wants to hear what she wants to hear"	175
3D.6.4	"I don't want this to happen to me"	176
3D.6.5	Little hope	178
3D.6.6	"Who to call"	180
3D. 7	DISCUSSION AND DECISION MAKING	182
3D.7.1	"Told not involved"	182
3D.7.2	"Being on the same page"	184
3D.8	SUPPORT FOR PATIENTS	186
3D.8.1	Spiritual support	186
3D.8.2	"Until nature takes its course"	189
3D.8.3	Presence	191
3D.8.4	"Noise is like normal"	194
3D.8.5	Patient's advocacy	194
3D.8.6	Private room	196
3D.9	SUPPORT FOR FAMILIES	197
3D.9.1	Support person	197
3D.9.2	Respect	199
3D.9.3	Open access	201
3D.9.4	"Staying with them"	202
3D.9.5	Gradual preparation	205
3D.9.6	Hospitality	207
3D.10	SUPPORT FOR NURSES	208
3D.10.1	"Just to talk with somebody"	209
3D.10.2	Team work	210
3D.10.3	Training	211
3D.10.4	Shift changes	213
3D.10.5	Time to adjust	214
3D.11	CONCLUSION OF THE FINDINGS	215

3D.12 SUMMARY 220

CHAPTER 4: BEST PRACTICE GUIDELINES FOR INTENSIVE CARE NURSES ON END OF LIFE CARE

4.1 INTRODUCTION 221
4.2 RESEARCH METHODS 222
4.2.1 Logical Reasoning 222
4.2.1.1 Inductive reasoning 222
4.2.1.2 Deductive reasoning 222
4.3 DEVELOPMENT OF BEST PRACTICE GUIDELINES 222
4.3.1 Integration and synthesis of conclusions and development of best practice guidelines 223
4.3.2 An outline of conclusions drawn from step 1 to step 4 (stage I) 224
4.3.2.1 Step 1: systematic review 224
4.3.2.2 Step 2: Experiences of family members on end-of-life care 227
4.3.2.3 Step 3: Experiences of critically ill patients on comfort care 230
4.3.2.4 Step 4: Intensive care nurses' experiences of end-of-life care 232
4.4 BEST PRACTICE GUIDELINES ON END-OF-LIFE CARE FOR INTENSIVE CARE NURSES 244
4.4.1 Communication recommendations 245
4.4.2 Caring recommendations 252
4.4.2.1 Basic physical caring 252
4.4.2.2 Emotional caring 254
4.4.2.3 Spiritual caring 254
4.4.2.4 Presencing 256
4.4.2.5 Support 257
4.4.2.6 Respect 260
4.4..3 Negative factors impacting on caring recommendations 262
4.4 SUMMARY 264

CHAPTER 5: VERIFICATION OF THE BEST PRACTICE GUIDELINES ON END-OF-LIFE CARE

5.1 INTRODUCTION 265
5.2 METHODOLOGY OF VERIFICATION OF THE BEST PRACTICE GUIDELINES 265
5.2.1 Target population 265
5.2.2 Sampling and sample 266
5.2.3 Verification procedure 266
5.2.4 The AGREE II Instrument 267
5.2.5 Validity and reliability of the AGREE II instrument 268
5.3 RESULTS OF VERIFICATION OF THE BEST PRACTICE GUIDELINES 268
5.3.1 Scope and purpose 269
5.3.2 Stakeholder involvement 270
5.3.3 Rigour of development 271
5.3.4 Clarity of presentation 272
5.3.5 Applicability 273
5.3.6 Editorial independence 274
5.4 OVERALL GUIDELINE ASSESSMENT 275
5.5 SUMMARY 280

CHAPTER 6: EVALUATION OF THE STUDY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

6.1 INTRODUCTION 281
6.2 EVALUATION OF THE STUDY 281
6.3 LIMITATIONS 297
6.4 RECOMMENDATIONS 298
6.4.1 Recommendations for management 298
6.4.2 Recommendations for nursing education 298
6.4.3 Recommendations for clinical practice 299
6.4.4 Recommendations for further research 300
6.5 CONCLUSION 300

LIST OF REFERENCES 302

APPENDICES 317

APPENDIX A	Approval from Post Graduate Committee	317
APPENDIX B	Ethics clearance certificate (University of the Witwatersrand)	318
APPENDIX C	Ethics clearance certificate (University of Pretoria)	319
APPENDIX D	Approval from Gauteng Department of Health	321
APPENDIX E	Approval from Charlotte Maxeke Johannesburg Hospital	324
APPENDIX F	Approval from Chris Hani Baragwanath hospital	325
APPENDIX G	Data extraction form	326
APPENDIX H	Quality assessment of quantitative studies	327
APPENDIX I	Quality assessment of qualitative studies	328
APPENDIX J	Family member information letter	329
APPENDIX K	Family member consent form for inclusion in the study	330
APPENDIX L	Family member consent form for tape recording	331
APPENDIX M	Family member's interview guide	332
APPENDIX N	Analyzed family member's transcript	333
APPENDIX O	Simplified acute physiological score(SAPS II)	337
APPENDIX P	Patient's information letter	338
APPENDIX Q	Patient's consent form for inclusion in the study	339
APPENDIX R	Patient's consent form for tape recording	340
APPENDIX S	Patient's interview guide	341
APPENDIX T	Analyzed patient's transcript	342
APPENDIX U	Intensive care nurses' information letter	346
APPENDIX V	Intensive care nurses' consent form for inclusion in the study	347
APPENDIX W	Intensive care nurses' consent form for tape recording	348
APPENDIX X	Intensive care nurses' focus group discussion guide	349
APPENDIX Y	Analyzed intensive care nurses' transcript	350
APPENDIX Z	Common themes from the four sources: Steps 1-4 of stage I	353
APPENDIX AA	AGREE II INSTRUMENT	354
APENDIX AB	Panel of experts information letter	358
APPENDIX AC	Panel of experts' consent form	359

LIST OF FIGURES

Figure		Page
2.1	A summary of the process and methodology of guideline development	19
3A.1	A summary of the presentation of chapter 3A	28
3A.2	Flow diagram of the selection process for articles used in the study	35
3B.1	A summary of the presentation of chapter 3B	64
3C.1	A summary of the presentation of chapter 3C	118
3D.1	A summary of the presentation of chapter 3D	163
4.1	A summary of the presentation of chapter 4	221
5.1	A summary of the presentation of chapter 5	265

LIST OF TABLES

Table		Page
1.1	An overview of research design and method	15
3A.1	List of included studies in the final review	36
3A.2	Results of methodological assessment of qualitative studies (n=11)	39
3A.3	Results of methodological assessment of quantitative studies (n=12)	40
3A.4	Summary of the results of studies (n=23) included in the systematic review	42
3B.1	Biographic information of family members' participants	72
3B.2	Themes and sub-themes emerging from family participants	73
3B.3	Theme one and its sub-themes	73
3B.4	Theme two and its related sub-themes	85
3B.5	Summary of theme three including its sub-themes	97
3B.6	Theme four and its related sub-themes	103
3B.7	Summary of the fifth theme and its sub-themes	110
3C.1	Demographic information of patient participants	126
3C.2	Themes and sub-themes emerging from patient participants	126
3C.3	Summary of theme one and its linked sub-themes	127
3C.4	Summary of the second theme and its associated sub-themes	140
3C.5	Summary of theme three and its related sub-theme	145
3C.6	Summary of the fourth theme and its correlated sub-themes	146
3C.7	Summary of theme five and its sub-themes	155
3D.1	The profile of nurse participants in the focus group discussion (n=24)	170
3D.2	Themes and sub-themes emerging from nurse participants	171
3D.3	Summary of theme one and its related sub-themes	172
3D.4	Summary of theme two and its interrelated sub-themes	182
3D.5	Summary of theme three and its linked sub-themes	186
3D.6	Summary of the fourth theme and its associated sub-themes	197
3D.7	Summary of theme five and its associated sub-themes	209
4.1	Classification of the strengths of evidence (McSherry et al.,	224

	2002:11)	
4.2	Integration and synthesis of conclusions from step 1-4 and recommendations	237
5.1	Verifiers' assessment of the scope and purpose	269
5.2	Verifiers' assessment of the stakeholder involvement	270
5.3	Verifiers' assessment of rigour of development	271
5.4	Verifiers' assessment of the clarity of presentation	273
5.5	Verifiers' assessment of applicability	273
5.6	Verifiers' assessment of the editorial independence	274
5.7	Verified best practice guidelines for intensive care nurses on end-of-life care	276

CHAPTER 1
OVERVIEW OF THE STUDY

1.1 INTRODUCTION

This chapter provides an overview of the study. In it, the background to the study is described followed by the problem statement, purpose of the study, research questions, and objectives. Significance of the study including the researcher's paradigmatic perspectives and relevant definitions have also been described. An overview of the methodology used follows including research design, study population, sampling procedures, data collection methods and data analysis procedures. In addition, measures to ensure validity and reliability have been described including ethical considerations.

1.2 BACKGROUND TO THE STUDY

End-of-life (EOL) care is an important international critical care issue, and currently provides a focus for health care policy and standards of practice in the intensive care unit (ICU). While society holds that intensive care is delivered in a highly technical area with a strong focus on cure and recovery, mortality rates in this specialty remain at approximately 20% (Coombs & Long, 2008). The management of patients at EOL is concerned with shifting the focus of care from curing disease to maximizing comfort and ensuring the needs of the patient and family (Carey & Cosgrove 2006).

EOL, also known as comfort or palliative care, is a comprehensive approach to treating the symptoms of illness when cure is not possible (Latour, Fulbrook & Albarran, 2009; Wright, 2009; Ott, 2010). It focuses on the physical, psychological, and spiritual needs of both the patient and the family (Hurley, 2010). The goal is to achieve the best quality of life available by relieving suffering, controlling pain, achieving maximum independence, making the patient as comfortable as possible as well as respecting the patient's culture, beliefs and values (Wright, 2009; Zomorodi & Lynn, 2010a:90; Gristina, Gaudio, Mazzon, et al., 2011).

It is reported that the severity of illness of hospitalized patients has progressively increased over recent decades (Carlet, Thijs, Antonelli et al., 2004:440). Most patients are admitted to the ICU with the goal of reversing their organ dysfunction at least to the extent that they no longer require intensive care and when this goal appears unattainable, the emphasis is shifted towards addressing EOL issues (Sarnik & Meert, 2007:104). As a result, the mission of the intensive care has expanded to encompass the provision of the best possible care to the dying patients and their families (Carlet et al., 2004:440).

In most cases, critically ill patients are increasingly staying in the ICU until death because they need specialized care and treatment (Yoo, Lee & Chang, 2008). Due to this, discussions on improving the quality of EOL care regularly occur in the ICU owing to it being a place where the transition from potentially curative to palliative treatment occurs (Carey & Cosgrove, 2006). The unpredictability of the advanced disease trajectory makes dying in the ICU a distinct possibility for many patients with advanced chronic illness who have been admitted to the ICU, and because of these uncertainties, quality EOL care is increasingly recognized as a key component of critical care nursing practice (Goodridge, Duggleby, Gjevre et al., 2008:163).

Good nursing care to ICU patients on the edge of life is based on nurses' understanding of each patient's situation which is extremely complex and afflicting (Reidun, Hedelin & Athilin, 2007). This good nursing care as stated by these authors depends on several basic conditions such as: continuity, knowledge, competence and cooperation, and includes clear goals to give EOL care in a timely and effective manner. As highlighted by Carlet et al. (2004:448), nurses often have closer and more prolonged contact with patients and their families and may provide valuable insights to the patients' or their familys' feelings and opinions. These authors also state that despite the fact that they are not expected to make EOL decisions, they are important collaborators who can facilitate the process and help patients and families to cope with their inevitable distress.

In addition, the scope of practice of the South African nursing council (2008) established under the nursing Act, 2005 indicates that the scope of practice of a registered nurse shall entail the care of the dying patient and the care of a recently deceased patient within the

execution of the nursing regimen. Moreover, the nurse should do all that benefits the patient or protect the patient from harm in terms of the principles of beneficence and nonmaleficence (Mohanti, 2009).

While improvements in EOL care are apparent, evidence suggests persistent shortcomings in nurses' ability to meet the needs of the dying patients. For example, concern exists among educators, healthcare professionals and researchers over the state of EOL care (Schlairet, 2009). In addition, shortfalls in formal EOL educational preparation for nurses at graduate, undergraduate and professional developed levels have been described by various authors (Ferrell & Coyle, 2002; Mallory, 2003; Reb, 2003). It has been observed that nurses are working in hospitals without knowledge of how best to meet patients' and families' comfort measures in ICU (Malloy, Ferrell, Virani et al., 2006). Also, there is evidence to suggest that patients at EOL do not always receive the care they perhaps desired (Thompson, Antonelli & Carlet et al., 2004).

To date, there are no published guidelines defining EOL care for critically ill patients, their families and intensive care nurses in South Africa. Based on the above mentioned points of views, it is apparent that there is a need to improve the quality of EOL care in the ICU. To achieve this, there is a need for best practice guidelines on EOL car for intensive care nurses. The principle benefit of guidelines in general is to improve the quality of care that is received by patients regardless of where or by whom the care is provided (Pasman, Hanssen-de Wolf, Hesselink, et al., 2009:79). To add on this, in order to meet consumer expectations for quality care, healthcare professionals are required to apply knowledge and expertise that reflects current best practice guidelines that are intended to offer concise instructions on how to provide healthcare services, with their potential to improve the process of care as well as patient health outcomes (MacLeod, Harrison & Graham, 2002). This study therefore aimed to develop guidelines in an attempt to define evidence-based best practices in the delivery of EOL care in the ICUs.

1.3 PROBLEM STATEMENT

Currently, intensive care units admit critically ill patients with different diagnoses including multiple organ dysfunction, severe trauma and chronic cardiovascular diseases among others. A proportion of these patients die in the ICU after a decision has been made to limit life-sustaining therapy (Carey & Cosgrove, 2006).

Despite the availability of a wide range of EOL care studies, there appears to be inadequate knowledge of how best intensive care nurses can provide ethical, quality, humane, holistic and comfort care for patients during their dying process in the ICU. The biggest misunderstanding about EOL care is that it is just about dying, and giving up on a patient; to the contrary, EOL care is about quality of life, regardless of how long that life might be (Stokowski, 2010). This study aimed at developing best practice guidelines for EOL care for intensive care nurses and it was anticipated that these guidelines will influence nursing practice, nursing education and policy making in the ICU.

The researcher sought to answer the following questions:

- What is the current discourse about end-of-life care for intensive care nurses in the intensive care unit?
- What are the intensive care nurses' experiences of end-of-life care in the intensive care unit?
- What are the experiences of adult critically ill patients admitted to the ICU with regard to comfort care?
- What are the ICU patients' family members' experiences with regards to the end-of-life care?
- What should best practice guidelines for end-of-life care for intensive care nurses involve?

1.4 PURPOSE OF THE STUDY

The purpose of this study was to develop best practice guidelines for end-of-life care for intensive care nurses in adult ICUs at tertiary level III hospitals in Gauteng province.

1.5 RESEARCH OBJECTIVES

- To search and analyze for quality research discourse on end-of-life care by means of a systematic review
- To search for evidence on end-of-life care through interviews with family members, interviews with critically ill patients and focus group discussions with intensive care nurses
- To develop best practice guidelines for intensive care nurses on end-of-life care
- To verify the tentative best practice guidelines for intensive care nurses using an Appraisal of Guidelines Research and Evaluation (AGREE) II instrument

1.6 ARGUMENT AND RATIONALE FOR THE STUDY

While guidelines on EOLC exist internationally (Truog, Campbell, Curtis, et al., 2008; http://www.health.nsw.gov.au; http://www.guideline.gov; http://www.viha; http://www.thehastingscenter.org, there are no national guidelines that have been developed in South African context on EOL to guide intensive care nurses when caring for patients at the EOL. What is known is that several protocols are available in South African ICUs for critically ill patients in general, among others: protocols on how to perform certain procedures and how to administer certain medications.

Due to the quadruple burden of disease in South Africa, ICUs often admit a high number of patients most of whom die after a decision has been made to limit life sustaining treatment. This decision is often known as ‘not for escalation of treatment’ or ‘not for resuscitation’, due to the irreversible/incurable nature of the patient’s illness. The frequency of this occurrence in this setting with a concomitant lack of guidelines prompted the researcher to carry out this study in order to develop guidelines for nursing care of these patients at EOL. In order to develop these guidelines, the researcher conducted a systematic review so as to obtain all the

necessary information on EOL care in the ICU. The experiences of the patients, families and the nurses in the South African ICUs were also elicited and used as a source of evidence in the guideline development. This made the guidelines much more appropriate to this setting because the voices of local people were used rather than those from other countries which may not have the same challenges or differences as in South Africa.

In this study, the patients' experiences towards EOL care were considered to be very important because the patients are the persons receiving intensive care hence their views of care received and care expected during their critical care was vital. On the other hand, family members are intimately involved in their loved ones' care and are most affected during EOL care so their experiences of care observed and personally experienced or received care was of importance in the development of the guidelines.

Above all, nurses are individuals most involved in giving comfort care thus their experiences of the care given to family members and patients including their experiences of being cared for and supported during their nursing care was considered as an important factor in the guidelines development.

In summary, the best practice guidelines developed from this study will enable intensive care nurses to put into practice what evidence indicates is of value to the patients and their families during the dying process. This means providing care in a way that improves the comfort and quality of patients' life despite of the impending death. On the other hand, intensive care nurses will benefit from the different approaches on how to handle patients at EOL including their families as well as coping strategies as they render such care. Moreover, the management at large will be able to make informed decisions considering the existence of the patients', families' as well as nurses' preferences during EOL care hence quality care.

1.7 PARADIGMATIC PERSPECTIVE

A paradigm is a world view, a general perspective on the complexities of the real world (Polit & Beck, 2012). This research was therefore based on the following assumptions:

1.7.1 Meta-theoretical Assumptions

Meta-theoretical assumptions are non-testable beliefs that are accepted to be true by the researcher (Pitacco, Silvestro & Drigo, 2001:27). These meta-theoretical assumptions reflect the researcher's view of a person, environment, nursing and health/illness. The researcher's meta-theoretical assumptions regarding these concepts therefore were as follows:

The person

The person in this case includes the patient at end of life/dying patient, the patient's significant others and the intensive care nurse. The dying patient is a person in a critical situation of life instability. It is a person in a vulnerable situation for whom this goal of cure is no longer possible. The care of such a patient(s) therefore must switch to comfort measures that enhance humanity while they approach death. On the other hand, the ICU patient's significant others are always under stress and experience anxiety due to the critical illness and the imminent death of their loved one. These family members need various kinds of support (emotional, social, spiritual, psychological, physical) during this time. Understanding how families make sense of this experience may help nurses to not only focus on the dying patient but also on the delivery of family centred care. In addition, the nurse is also central in the context of this study. The nurse is present at the patient's bedside twenty four hours a day, and is therefore essential to the provision of quality EOL care. For the nurse to be able to render such a quality care to the dying patient and his or her family, there is a need for knowledge, skills and strategies to cope with all the challenges that come along with EOL care. Support from the institution and colleagues is also of benefit and may keep the nurse strong emotionally.

The environment

The environment is the total context of a persons' (dying patient, family and nurse) surroundings that has an influence on his or her physical, psychological, emotional and behavioural well being. Any environmental changes may require greater energy to adjust to the situation. In this study, the environment is the ICU setting. The ICU environment is subject to complex technological advances. This new, unfamiliar and complex setting can be a source of physical, emotional, psychological and spiritual stress to the dying patient as well as to the family (Pitacco, et al., 2001). An admission of a patient into the ICU environment

can be scary and stressful to the patient and the family as this indicates the seriousness of the illness. The burden on the environmental stress to the family could be increased by the news that the patient is facing an impending death. This environmental stress may also extend to the nurses caring for such patients and families as they may also start grieving the loss of the patients with whom they may have developed a bond in the caring process.

Nursing

Caring for the dying patient and his or her family requires a nurse who can provide competent and holistic care through the integration of advanced-level knowledge and skills. Even though restoring health and cure may not be possible, nurses need to realize that nursing should entail doing all that promotes comfort and protects the patient from harm in terms of the ethical principles (Jones & Bartlett, 2006).

Health/Illness

The person at EOL is a seriously ill person for whom initial care is not even aimed at restoring partial health, but aims towards the stabilisation of the condition so that it becomes a 'manageable illness' (Pitacco, et al., 2001). Health and illness is a process which begins from illness and moves towards health however, the results of intensive intervention cannot always be predicted, there may be no progress to health. While society holds that intensive care is delivered in a highly technical area with a strong focus on health restoration, mortality rates in this specialty remain at approximately 20% (Coombs & Long, 2008). This therefore means that despite the efforts of the intensive care team, death is eventually the end result.

Having discussed meta-theoretical assumptions, the following section will deal with theoretical assumptions related to EOL care.

1.7.2 Theoretical Assumptions

The following theoretical statements derived from Waldrop and Kirkendall (2009); Edwards, Pang, Shiu and Chan (2010); Olsen, Swetz and Mueller (2010); in relation to EOL care are applicable to this study:

- The basic duty of health care providers is to preserve human health and life, but it should be realized that death is the inevitable destiny of mankind.
- Designating a period of time as “the EOL” is a necessary first step to improving care for people approaching the EOL.
- Health care providers need to help patients and families minimize suffering and maximize comfort by offering appropriate medical care that is neither excessive nor negligent.
- Dealing with a patient at the EOL, aiming to improve quality of life, and planning for EOL care requires an understanding of the patient's state from a medical, social, spiritual, and psychological point of view.
- Nurses should develop an interpretation of what type of care is in the patient’s best interest based, in part, on their understanding of the patient's health situation and dying status.
- A focus on comfort care goals is considered best practice care for people approaching death; comfort care is interdisciplinary care focused on the relief of suffering and support for the best quality of care for people facing a life-threatening illness, and for their family members, regardless of the stage of the disease.
- When a patient is recognized as dying, it is socially acceptable to allocate the remaining time and effort exclusively toward achieving physical, emotional, and spiritual comfort rather than continuing to pursue medical interventions aimed at recovery. Justification for a transition to comfort care goals is based on agreement that there are no medical interventions available to reverse further decline and that the patient's quality of life is already compromised.

1.7.2.1 Definition of terms for the purpose of this research

End-of-life- Is the period of time marked by disability or disease that is progressively worse until death (http://www.mywhatever.com).

End-of-life care- The care and supportive services that an individual with an advanced disease or trauma and his/her family receives after the decision has been made to limit life-sustaining therapy (Latour et al., 2009; Ott, 2010).

Comfort care- Also known as end-of-life or palliative care is a comprehensive approach to treating the symptoms of illness when cure is not possible. Comfort care focuses on the physical, psychological, and spiritual needs of both the patient and the family. The goal is to achieve the best quality of life available by relieving suffering, controlling pain, achieving maximum independence, making the patient as comfortable as possible as well as respecting the patient's culture, beliefs, and values (Wright, 2009; Zomorodi & Lynn, 2010a:90; Gristina et al., 2011). Comfort care in this study refers to providing nursing care that meets the patients' and families' physical, emotional, psychological and spiritual needs.

Palliative critical care- Means the specialized care of people who are dying- care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. This term is generally used with people who have an active, progressive and advance disease, with little or no prospect of cure (Barwich, Hawley, Kennedy, et al., 2008; Hurley, 2010). Palliative critical care was used in this study referring to the specialized care given to the patients whose restorative treatment has been withheld or withdrawn.

Withholding and withdrawing treatments - While withholding treatment is a planned decision not to start a treatment, withdrawing treatment is a planned decision to stop a treatment that has already been started (Latour, et al., 2009). While these terms are commonly used during EOL care, they were not often used in the study sites. Instead, the terms "not for escalation of treatment" or "not for resuscitation" or "for palliative management" were used. These terms were used on patients whose decision had been made to limit life sustaining treatment due to their poor prognosis and the shift from cure to comfort care.

Best practice guidelines - Are systematically developed statements used to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances (DiCenso, Guyatt & Ciliska, 2005).

Intensive care unit (ICU) – Is a specifically designated unit, with specialized equipment and skilled personnel for the care of critically ill patients requiring immediate and continuous

attention (Bersten, Soni & Oh, 2003). Trauma, cardiothoracic and multidisciplinary units were used in this study as they were considered by the researcher to be homogenous and represented highly specialized ICUs that accept critically ill patients from both medical and surgical disciplines.

A critically ill patient – Is characterized by the presence of actual or potential life-threatening health problems, which include the requirement for continuous observation and interventions in an intensive care unit to prevent complications and restore health where possible (Pitacco, et al., 2001). For the purpose of this study, these critically ill patient health problems encompassed both medical and surgical diagnostic categories.

Family – Family is defined by the patient or in the case of minors or those without decision making capacity by their surrogates. The family may be related or unrelated to the patient. They are individuals who provide support and with whom the patient has a significant relationship (Davidson, Powers & Hedayat et al., 2007). They are individuals of significant importance to the dying person (Fridh, Forsberg & Bergbom, 2009b:112). In this study, the family refers to the people who are closely related to the patient (father, mother, son, daughter, brother, sister, uncle, aunt). These people were purposively selected and interviewed. In most instances, the family/friends chose such close persons to the patient to participate during the interview.

Intensive Care Nurse – Is a person who provides competent and holistic care for the critically ill patient through the integration of advanced-level knowledge, skills and humanist values (Williams, Schmollgruber & Alberto, 2006:399). For the purpose of this study, registered nurses trained in critical care working in the selected ICUs formed part of the study participants.

1.7.3 Methodological Assumptions

Methodological assumptions are statements that are taken for granted or are considered true even though they have not been scientifically tested (Burns & Grove, 2007). This research is based on an interpretive tradition whereby knowledge or reality is constructed by the description of peoples' intentions, beliefs, values and reasons, meaning-making and self-understanding (Henning, 2004:20). This construction of understanding is subject to revision, thus the construction may be reconstructed (Babbie & Mouton, 2001). In this study, the views and "understandings" of the intensive care nurses, patients and family members on end-of-

life/comfort care have been constructed through focus group discussions for nurses and semi structured interviews for patients and families.

Patients at EOL or receiving EOL care and family members have been referred by Bigatello, George and Hurford (2003:178) as special cases of persons who have already accepted the inevitability of death. The authors state that these patients clearly will not derive personal benefit from any research and should not be confronted with requests for participation in research. However, it is also true that some of these patients and families have reached a stage of sufficient serenity to volunteer their participation in research as an ultimate act of beneficence. Their wishes should be satisfied when possible, recognizing that these are extremely delicate situations.

For this reason, the researcher purposively selected a sample of family members whose relatives received end of life care in the ICU. The sample also included those patients who survived intensive care and were discharged to the ward so as to elicit their views on comfort care while in the ICU as they had had an experience of nursing care in the ICU though they may not have been treated as requiring end-of-life care.

The qualitative enquiry into the views and understanding of comfort or EOL care by intensive care nurses, patients and family members was preceded by a systematic review. The international interest in evidence-based practice arising largely out of the work of the Cochrane collaboration focuses on the systematic review of evidence as a basis for the development of evidence-based guidelines and their utilization in practice (http://www.joannabriggs.edu.au, 2008).

Evidence is a construct that has multiple realities of which randomised control trials and the knowledge it generates are one but one form. Evidence obtained from all the sources was integrated and synthesised thus reconstructing the understanding of EOL care in the ICU. Evidence-based practice, which is based on best practice guidelines, is the careful and practical use of current best evidence to inform practice decisions (DiCenso, et al., 2005). Initially, it was generally accepted that evidence-based research is restricted to randomised

controlled trials and meta-analysis. However, this is not always possible in evidence based research and critical care nursing practice as evidence-based research involves tracking down the best external evidence with which to answer clinical questions (Elman, 2006:106). In addition, while randomised controlled trial is probably the "best" approach to generating evidence of effectiveness, nurses, medical practitioners and allied health professionals are concerned with more than cause and effect questions, and this is reflected in the wide range of research approaches utilized in the health field to generate knowledge for practice (http://www.joannabriggs.edu.au, 2008).

Joanna Briggs Institute (http://www.joannabriggs.edu.au, 2008), suggests that the reviews that include both or either qualitative evidence and quantitative evidence are of importance to most practitioners and for this reason, both high quality quantitative and qualitative studies other than randomised controlled trials were included in the systematic review. Verification of the tentative best practice guidelines was then conducted by a panel of experts so as to assess the accuracy and quality of best practice guidelines, refine and further develop the best practice guidelines and ensure the content validity of the best practice guidelines.

Nursing science becomes a practice with its purpose being to provide current knowledge to be used to generate guidelines for actions in order to make practice more effective (Barrett, 2002). These actions can only be rendered in a specific context, in this case the ICU, where patients' needs and preferences are taken into consideration. The researcher conducted this study with the aim of generating knowledge so as to develop best practice guidelines that could improve nursing practice.

1.8 RESEARCH DESIGN AND METHOD

1.8.1 Overview of research design and method

Both quantitative and qualitative approaches were used in order to meet the objectives of this study. The study was conducted in three stages as described below.

Stage I addressed the first and second objectives of this study and it comprised the search for quality research evidence which was done in four steps including:

- Step 1-Collecting evidence on EOL care by means of a systematic review
- Step 2-Collecting evidence on family members' experiences of EOL care by means of semi structured interviews
- Step 3- Collecting evidence on critically ill patients' experiences of comfort care after their discharge to the step down facility by means of semi structured interviews
- Step 4- Collecting evidence on intensive care nurses' experiences of EOL care through focus group discussions

Stage II addressed the third objective of this study and it involved the development of best practice guidelines for intensive care nurses on EOL care. The process of guideline development included synthesising and integrating the findings from the four steps in stage I, formulating guidelines in a form of recommendations and categorising the strength of evidence.

Stage III addressed the fourth objective of this study and it dealt with the verification of the tentative best practice guidelines for intensive care nurses using an Appraisal of Guidelines Research and Evaluation (AGREE) II instrument by a panel of experts from different disciplines.

Table 1.1 below provides an overview of research design and method. These regard to data collection procedures, sample and sampling methods and methods of analysis that were used in the different stages of the study.

Table 1.1 An overview of research design and method

Stage	Step	Objective	Data collection	Sampling and sample	Data analysis
I	1	Systematic review	Literature retrieval from: -Multiple electronic data base -Journal hand search -Reference lists of articles -Books, theses and Government documents.	-Purposive sampling -n=23 articles on EOL in the ICU	Meta-synthesis
	2	Experiences of family members on EOL care	Semi structured interviews	-Purposive sampling -n=17 family members	Tesch's method of qualitative analysis
	3	Experiences of critically ill patients on comfort care	Semi structured interviews	-Purposive sampling -n=16 critically ill patients	Tesch's method of qualitative analysis
	4	Intensive care nurses' experiences of EOL care	Focus group discussions	-Purposive sampling -n=3 focus groups -Sample size (n=24 nurses)	Long-table approach of data analysis
II	-	Development of best practice guidelines	Conclusions drawn from steps 1,2,3 and 4	Guidelines related to communication, caring and negative factors impacting on end-of-life care developed	Integrating, synthesising and categorising strength of evidence
III	-	Verification of best practice guidelines	Use of AGREE II instrument to evaluate guidelines	-Purposive sampling -n=4 expert verifiers	Recommendation modifications

1.8.2 Validity and reliability

Measures of validity and reliability applied mainly to stage I of this study. While this has been described in detail in chapter 2 and 3A, this section provides an overview of how validity and reliability was ensured as follows:

During systematic review (step 1), stringent measures of validity were implemented so as to ensure representativeness of the literature sources used. These measures included appraisal of all literature prior to inclusion in the systematic review and use of multiple electronic databases, journal hand searches and reference lists of relevant articles for retrieval so as to reduce bias. In addition, reliability was maintained by ensuring consistency in the selection of literature by adherence to predetermined inclusion criteria. On the other hand, a co-reviewer was involved during systematic review so as to ensure accuracy and reliability of selected information.

In steps 2, 3 and 4, Lincoln and Guba's criteria for ensuring trustworthiness of qualitative research were applied during semi structured interviews and focus group discussions. The five main aspects include credibility, transferability, dependability, authenticity and conformability (Lincoln & Guba, 1985). Expert verifiers assessed the guidelines' validity using the AGREE II instrument. AGREE II instrument assesses the methodological rigour and transparency in which a guideline is developed. Moreover, it is a valid and tested tool by the AGREE research trust hence its validity and reliability is assured (AGREE research trust, 2009).

1.8.3 Ethical considerations

A detailed description of ethical considerations is provided in chapter 2. Prior to the commencement of the study, ethical clearance and permission to conduct the study were obtained from relevant university committees and the hospitals. Participation in the study was voluntary and participants were free to withdraw from the study at any time. Participants' right to privacy, anonymity and confidentiality were maintained throughout the study during tape recording, transcription of the data and handling of tape recorders.

1.9 PLAN OF THE STUDY

This study is presented as follows:

Chapter 1: Overview of the research study

Chapter 2: Research design and research method

Chapter 3A: Systematic review

Chapter 3B: Experiences of family members on end-of-life care

Chapter 3C: Experiences of critically ill patients on comfort care

Chapter 3D: Intensive care nurses' experiences of end-of-life care

Chapter 4: Best practice guidelines for intensive care nurses on end-of-life care

Chapter 5: Verification of the best practice guidelines on end-of-life care

Chapter 6: Evaluation of the study, limitations, recommendations and conclusion

1.10 SUMMARY

This chapter introduced the reader to the study. The problem statement, the research questions, the purpose and objectives of the study have been stated. Paradigmatic perspectives including relevant definitions have also been described. In addition, an overview of the research methodology including the plan of research action has been provided.

The following chapter provides the research design and research methods applicable to this study.

CHAPTER 2
RESEARCH DESIGN AND METHOD

2.1 INTRODUCTION

In the previous chapter, an overview of the study was provided. In this chapter, an overall research design and methodology of each of the three stages of the study is described. For easy reading, a detailed presentation of research design and methods is presented in the relevant chapter in the context of the relevant stage/step of the study.

The purpose of this study was to develop best practice guidelines for end-of-life care for intensive care nurses in adult ICUs at tertiary level III hospitals in Gauteng province.

In order to meet this purpose, the following objectives were set:

- To search and analyze for quality research discourse on end-of-life care by means of a systematic review
- To search for evidence on end-of-life care through interviews with family members, interviews with critically ill patients and focus group discussions with intensive care nurses
- To develop best practice guidelines for intensive care nurses on end-of-life care
- To verify the tentative best practice guidelines for intensive care nurses using an Appraisal of Guidelines Research and Evaluation (AGREE) II instrument

Both quantitative and qualitative approaches were used to develop best practice guidelines on EOL care for intensive care nurses. The process of best practice guideline development was divided into three stages as illustrated in **figure 2.1.** This illustration is provided as a point of departure for the subsequent chapters.

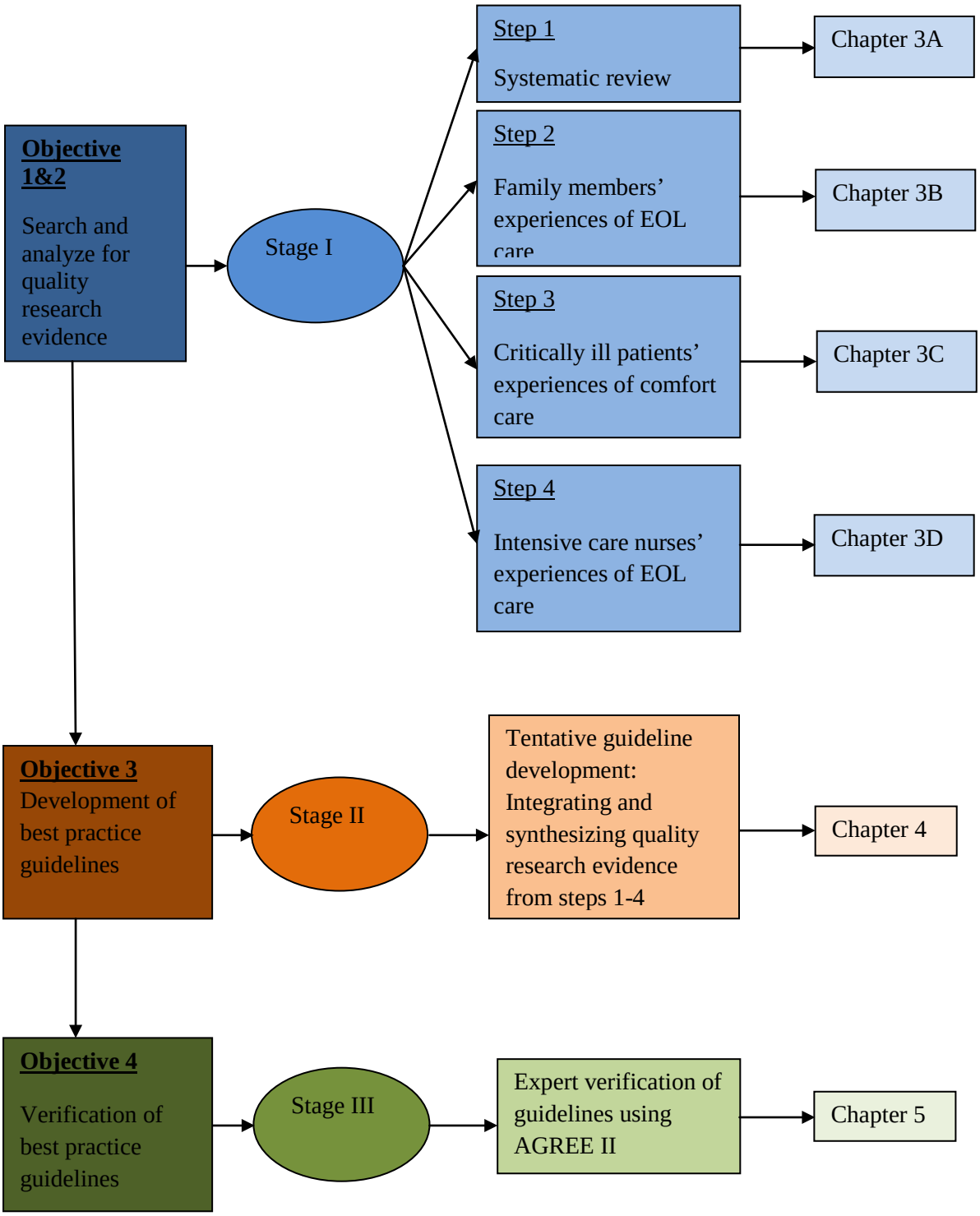


Figure 2.1 A summary of the process and methodology of guideline development

2.2 RESEARCH DESIGN AND METHODS

2.2.1 Stage I: search for quality research evidence

This stage refers to the first and second objectives of this study. This stage was initiated so as to provide current best information (Dicenso, Guyatt & Ciliska, 2005) on EOL care for intensive care nurses caring for the adult critically ill patients in Gauteng province, South African. The search for quality research evidence was conducted in four steps.

2.2.1.1 Step 1: systematic review

This step involved collecting evidence by means of a systematic review. A systematic review is a rigorous method of summarising the findings of studies that address a focused clinical question (DiCenso, et al., 2005:33). A systematic review was conducted in order to provide a rigorous review of quality research evidence, expert practitioners' opinions, patients' preferences and available resources (Burns & Grove 2007) to deliver recommended comfort care necessary at EOL. The systematic review is the critical step in the process of developing best practice guidelines as it is a strategy used to search for evidence (DiCenso et al., 2005). The process of systematic review included question formulation, conducting the literature search and data extraction, appraisal of retrieved literature and data synthesis as described in detail in the following chapter.

2.2.1.2 Step 2, 3 and 4: Experiences of end-of-life care

Steps 2, 3 and 4 involved collecting evidence on the family members', critically ill patients' and intensive care nurses' experiences of EOL care consecutively. To describe these lived experiences, a qualitative, exploratory, descriptive design was used. In step 2, evidence from family members' experiences of EOL care was elicited by means of individual semi structured interviews. Step 3 involved collecting evidence from the critically ill patients' experiences of comfort care by means of individual semi structured interviews. Step 4 involved collecting evidence on intensive care nurses' experiences of EOL care by means of focus group discussions. All these steps were conducted so as to provide research evidence for the development of best practice guidelines.

Qualitative research is a systematic, subjective approach used to describe life experiences and give them meaning. It focuses on understanding the whole; it explores the depth, richness and complexity inherent in phenomena (Burns & Grove 2007). In step 2, family members' experiences were explored in order to gain an understanding of their subjective experiences of EOL care. In step 3, critically ill patients' experiences of comfort care were explored in order to gain an understanding of their comfort in the ICU. In step 4, a qualitative approach was used since a subjective approach was taken to describe the ICU nurses' experiences of EOL care.

Exploratory studies set out to explore a relatively unknown field, of which the purpose is to gain new insights into the phenomenon under study, clarify central constructs and concepts and determine priorities for further research (Polit & Beck, 2012; de Vos, strydom, Fouche, et al., 2011). In this study the researcher set out to explore and gain insight into family members', critically ill patients' and intensive care nurses' experiences of EOL care.

Descriptive research is used to gain more information about characteristics within a particular field, and to provide a picture of a situation as it naturally occurs (Burns & Grove 2007:18). The study was descriptive as it provided an in-depth description of the study participants' experiences of comfort or EOL care.

2.2.2 Stage II: Development of best practice guidelines on end-of-life care

This stage refers to the third objective of this study. To achieve the development of best practice guidelines, conclusions drawn from stage I (steps 1-4) were synthesised and integrated to provide evidence for the development of BPG. Logical reasoning (deductive and inductive reasoning) was applied so as to develop best practice guidelines.

2.2.3 Stage III: Verification of best practice guidelines on end-of-life care

This stage refers to the fourth objective of this study. Best practice guidelines require verification before implementation so as to assess its accuracy and quality, refine and further develop the guidelines and ensure its content validity (AGREE Research Trust, 2009). For

this reason, best practice guidelines were verified by a panel of experts from different disciplines using AGREE II instrument. Feedback, recommendations, criticisms and suggestions were analyzed and incorporated into the best practice guidelines as presented in chapter 5.

2.3 RESEARCH SETTING

Research setting refers to specific places where information is gathered (Polit & Beck, 2012:49). The participant representatives were selected from adult ICUs (trauma, cardiothoracic and multidisciplinary units) at three tertiary level III referral hospitals in Gauteng. These institutions were considered by the researcher to be homogenous and that they represented highly specialized ICUs that accept critically ill patients from both medical and surgical disciplines. Patients admitted in these units are level three patients i.e. critically ill patients admitted to ICU located in a major tertiary referral hospital (Bersten, Soni & Oh, 2003). Considered of importance also was the fact that due to the nature of the patients' severity of illness admitted into these ICUs, nurses working in these ICUs have experience of nursing critically ill patients including patients at EOL.

2.4 RESEARCHER'S A PRIORI VIEW OF THE WORLD (STEPS 2, 3 AND 4)

A phenomenological study is a strategy of inquiry in which the researcher identifies the essence of human experiences about a phenomenon as described by the participants (Creswell, 2009). In this case, the nature of the researcher participant relationship has an impact on the collection and interpretation of data and the researcher influences people being studied and in turn is influenced by them (Burns & Grove, 2007). To interpret their experiences, the researcher must become closely involved in the subjects' experiences as well as being open to their perceptions rather than attaching his or her own meaning to their experiences (Brink, Van Der Walt & Rensburg, 2008; Burns & Grove, 2007).

During the research process, the researcher was working in the ICU hence had experienced and acquired knowledge on EOL care. Her daily interaction with the study participants also led to a bond which later contributed to the researcher participant relationship. During sample

selection, participants were purposively selected because of their experiences related to the study. The participants cooperatively carried out the study in that they provided guidance to the researcher who could not successfully carry out the study without them. Although the researcher defined the focus of the interviews, there was no fixed sequence of questions. The questions were addressed and tended to slightly change as the researcher gained insight from previous interviews. Participants were encouraged to raise important issues not addressed by the researcher. In this manner, the researcher and the participants were actively engaged in constructing a version of the world view with a common goal and making a sense of the interview experience.

The researcher conducted interviews and analysis concurrently and for her to become familiar with the data, she read and re-read the transcripts while recalling the experiences so as to become immersed in the data. This did not only enhance an understanding of what was going on in the study but it also enabled a dynamic interaction between the researcher and experiences of the data. During this process referred to as reflexive thought (Burns & Grove, 2007), the researcher explored personal feelings and experiences of EOL care that may have influenced the study and integrated understanding into the study. This eventually led to bracketing whereby the researcher avoided misinterpreting the phenomenon as it was being experienced by the participants by laying aside what she knew about experiences being studied (Creswell, 2009; Burns & Grove, 2007) in this case, EOL care in the ICU. Finally, as the relationships among the categories, participants, actions and events began to emerge, the researcher offered an interpretation of what was going on by understanding and explaining the findings.

2.5 MEASURES TO ENSURE TRUSTWORTHINESS APPLICABLE TO STEP 2, 3 AND 4

Lincoln and Guba's criteria for ensuring trustworthiness of qualitative research were applied. The four main aspects as discussed below according to Lincoln and Guba (1985) include credibility, transferability, dependability, conformability and authenticity.

Credibility is the ability of the researcher to establish confidence in the truth of the findings of a particular inquiry with reference to the participants and the context in which the study is

carried out (Polit & Beck 2012; de Vos, et al., 2011). Credibility was achieved in this study by:

- Prolonged engagement in the field. Prolonged engagement according to Rubin & Babbie (2010) is used to reduce the impact of reactivity and respondent bias, it assumes that a long lasting relationship with the researcher gives respondents less opportunity to give false information and makes them less inclined to withhold information. This was achieved in that the researcher was and continues to be involved in the ICU field by providing comfort care to the critically ill patients. Prolonged engagement with the participants was also maintained in that the researcher stayed in the field until data saturation occurred.
- Triangulation occurs when the researcher seeks evidence from two or more sources for data and interpretations (Rubin & Babbie 2010:232). This was achieved in the interview process as the researcher sort to clarify and understand the deeper meaning of the information provided in the previous interviews including its explanations from subsequent participants.
- The researcher wrote extensive observational field notes to supplement the findings as a form of ensuring referential adequacy (Burns & Grove, 2007; de Vos, et al., 2011). These notes were used in the results section to explain the activities and participants actions during the interview that could have reflected their reaction to a response such as crying, grimace to indicate pain among others.

Transferability also referred to as fittingness or applicability is the extent to which findings can be transferred to or have applicability in other settings or groups (Polit & Beck, 2012:585). The following strategies were implemented so as to ensure transferability of the study:

- A detailed description is provided of the process of data collection with sufficient detail and accuracy so as to allow judgements about transferability to be made by the reader.
- The researcher maximised the range of specific information that can be obtained from the context by purposively selecting participants and locations that fulfil the study

needs. Participants in this study were selected based on their experience of the phenomenon under study i.e. comfort or end-of-life care in the ICU.

Dependability refers to the extent in which another researcher can clearly follow the decision trail used by the investigator and arrives at the same or comparable, but not contradictory conclusions (Koch, 2006:92). This aspect was achieved by:

- The reader is provided with a clear description of the research methodology, justification of procedures, decisions and choices throughout the research process so as to ensure dependability of the study.
- Tape recorder was used to record each and every interview and thereafter complete verbatim transcription of all interviews was done.
- Data was stored safely in a computer to ensure retrieval when needed.
- Observational field notes were taken during or immediately after each interview to enrich the tape recorded data and to record impressions of the context.

Conformability refers to the potential for congruence between two or more independent people about the data's accuracy, relevance, or meaning (Polit & Beck, 2012:585). The following strategies were implemented so as to ensure transferability of the study:

- Literature has been utilised throughout the process of developing themes and discussing the data so as to examine whether themes and concepts extrapolated from the data are confirmed by literature.
- The researcher has accurately documented the strategies and process of the study including the research method design so as to provide the reader with the opportunity to audit the study.
- Samples of analysed transcripts have been provided in the appendix section. These include: one transcript from family participants, one from critically ill patients and a portion of focus group two discussions with intensive care nurses for auditing purposes (refer to **appendices N, T, Y** consecutively).

- A non-judgemental neutral stance was retained during interviews by asking open-ended questions to facilitate the expression of the respondents' own subjective view point as much as possible.
- Before the end of an interview, the respondent was requested to confirm that the responses given throughout the interview were an accurate reflection of the conversation and given an opportunity to further expand if need be until his or her view had been adequately expressed.

Authenticity refers to the extent to which researchers fairly and faithfully show a range of realities. This was achieved by:

- Describing the participants' experiences as they are lived in order to invite the readers into a vicarious experience of the lives being described as well as enabling them to develop a heightened thoughtfulness to issues being illustrated.

2.6 ETHICAL CONSIDERATIONS

According to Burns and Grove (2007), the goal of research is to generate sound scientific knowledge, which is possible only through the honest conduct, reporting and publication of quality research. In this regard, ethical review and clearance before conducting any research is necessary to ensure that the benefits of subjects outweigh the risks and that there is no research misconduct. Concerning this, the following ethical considerations were applied in this study:

- The research proposal and the instruments were submitted to the postgraduate Committee, Faculty of Health Sciences of the University of the Witwatersrand for permission to undertake the research. Permission was obtained (refer to **appendix A**).
- The research proposal and instruments were submitted to the Committees for Research on Human Subjects of the University of the Witwatersrand and Pretoria to ensure compliance with the ethical standards. The committees issued clearance certificates (refer to **appendices B** and **C respectively**).

- Permission to conduct the research was obtained from the Department of Health, Gauteng, and participating Hospital management (refer to **appendices D, E** and **F respectively**).
- Before inclusion in the study, a written informed consent to participate and to be tape recorded during the study were obtained from the family members, patients and nurse participants.
- To ensure confidentiality and anonymity of the participants, pseudonyms and numbers were used during data collection and reporting. All the tapes were and will be kept in a locked cupboard for two years until publication or up to six years if publication will not have been done, thereafter they will be destroyed. All the data were and will be kept safe under password protected computer. Participation in the study was voluntary and participants were allowed to withdraw from the study at any time without any consequences.

2.7 SUMMARY

In this chapter, an overall research design and method for stages I (steps 1-4), II and III were described. These three stages reflect the processes necessary in the guideline development. Common aspects in the different stages of the study such as research setting, researcher's a priori view of the world, measures to ensure trustworthiness and ethical considerations were also discussed in detail.

The following chapter presents a detailed research design and methods including the findings from the systematic review conducted in step 1.

CHAPTER 3A
SYSTEMATIC REVIEW

3A.1 INTRODUCTION

In the previous chapter, an overall research methodology and research design of the study was described. This chapter refers to step 1 of stage I of the study and it starts with providing a detailed research design and methods. Thereafter, the results of the systematic review are presented and discussed. Data sets were analyzed to find the interpretation of the primary research findings and their meaning in relation to End-Of-Life (EOL) care or comfort care. The search strategy results are described and a list of articles that were included in the study is provided. The results of methodological quality assessment are provided including the characteristics of the included studies. The results from this chapter contribute to the development of best practice guidelines in chapter 4. Refer to **figure 3A.1** for the summary of the presentation of this chapter.

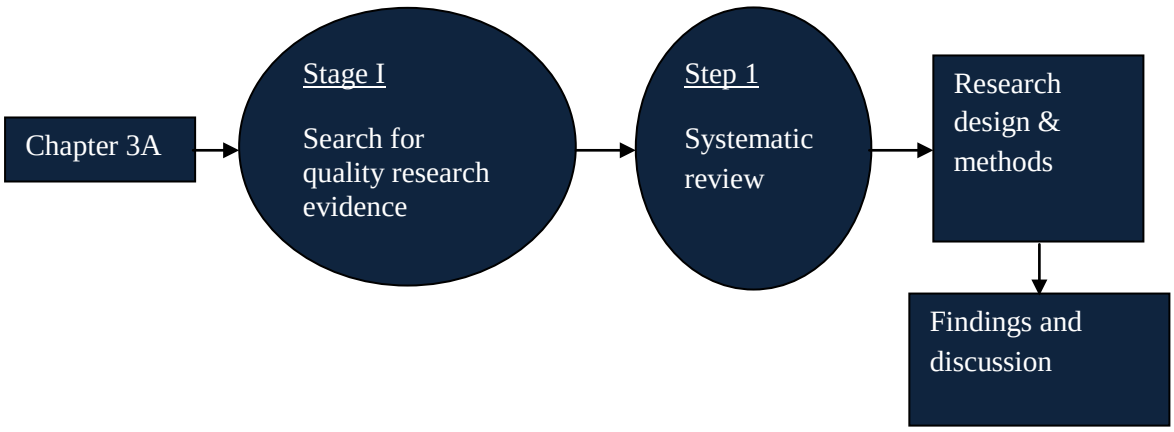


Figure 3A.1 A summary of the presentation of chapter 3A

3A.2 RESEARCH DESIGN

A systematic review was utilized in this step of the study.

3A.3 RESEARCH METHODS

3A.3.1 Target population

A systematic review of all available national and international sources of literature was conducted.

3A.3.2 Sampling and sample

All available national and international sources of literature were retrieved from electronic databases including SCOPUS, Science Direct, Pubmed, Cochrane, Medline and CINHAL. In addition to electronic searches, journal hand search, reference lists of articles, books, theses, Government documents and grey literature was also conducted. The review purposively considered integrative studies that dealt with end of life (comfort) care and critical care nursing. The search pathway was carried out using the search words comfort care, end-of-life care, palliative care, intensive/critical care, good death, decision making, withdrawal and withholding of treatment and futile care in the ICU.

Inclusion criteria for the systematic review:

- All studies with published abstracts and full text in English
- All peer reviewed research articles which were published in referenced journals from the year 2003 to 2011
- Both quantitative and qualitative studies
- Studies on adult ICU patient population

3A.3.3 Data collection procedure

Literature retrieval was conducted following inclusion criteria. Critical appraisal of sources was conducted prior to inclusion in the systematic review so as to ensure validity of the retrieved research. Data related to EOL care (comfort care) in nursing from critically

appraised literature were then extracted. Conclusions were drawn following description of issues extracted. These conclusions including the conclusions drawn from steps 2, 3 and 4 were used as evidence for the best practice guideline development.

The process of conducting a systematic review was applied as described by Dicenso, Guyatt and Ciliska (2005). This process included question formulation, conducting the literature search and data extraction, appraisal of retrieved literature and data synthesis. These processes are described in detail below.

3A.3.4 Question formulation

Based on the objective of this stage of the study and for the researcher to come up with information regarding care at the EOL, the following review questions were asked: What kind of EOL care is received by adult critically ill patients and their families in public sector ICUs in South Africa from intensive care nurses? What support do nurses need in the EOL caring process?

3A.3.5 Conducting literature search and data extraction

The systematic review was based on a systematic search on six databases including: SCOPUS, Science Direct, Pubmed, Cochrane, Medline and CINHAL. In addition to electronic searches, journal hand search, reference lists of articles, books, theses, Government documents and grey literature was also conducted. All studies were undertaken between the year 2003 and 2011 and all had investigated the concept of EOL care in the intensive care setting. The search was confined to this period (2003-2011) because during this period there have been many improvements in nursing education and much discussion on questions of end of life and comfort care in the ICU more especially in countries such as Europe and United States of America (USA) (Latour, Fulbrook & Albarran, 2009; Vincent, 2010). Moreover, an extended period of up to 10 years has also been suggested for a thorough search (Davies & Logan, 2012).

Studies which were identified during the data base search were retrieved based on the journal title followed by information in the abstract, if the abstract was inconclusive; a full report was

retrieved and evaluated against the inclusion criteria. Refer to **appendix G** for a standardized form used during data extraction. The process of searching and extraction continued until saturation. The review considered any qualitative or quantitative research studies that dealt with EOL (comfort) care and critical/intensive care nursing. Harden (2010) advocates the use of both qualitative and quantitative research in systematic reviews and she states that by including other forms of evidence from different types of research, mixed-methods reviews try to maximize the findings, and the ability of those findings to inform policy and practice.

Efforts to distinguish between independent studies and those repeated several times were made in order to minimize duplication and over emphasizing one aspect of the studies. To achieve this, the names of the principal investigators, the country, the study title, the journal name and the year of publication were recorded using a checklist specifically developed by the researcher (refer to **table 3A.1**) to capture the list of included studies. The focus was put on research findings and discussion so as to get the underlying meaning of the study findings and their interpretations based on the review question and specific objectives. Descriptive phrases and themes of the content on EOL care were identified. The categories were pooled together to find a common structure within which the results and meaning of the studies could be understood.

3A.3.6 Appraisal of retrieved literature

A critical appraisal of sources was conducted prior to inclusion in the systematic review. Joanna Brigs Institute has adopted a position that requires the critical appraisal of all papers selected for inclusion in a systematic review. Joanna Brigs Institute requires reviewers to use standardised critical appraisal instruments; and emphasises the need for evidence to be subjected to rigorous appraisal by two critical appraisers. The purpose of the appraisal is to include only those studies or reports that are of high quality and thus to exclude those of poor quality and ensure validity of the retrieved research (http://www.jbiconnect.org/connect/info/about/jbi ebhc approach.php). Studies were screened and appraised using different check lists as described below:

3A.3.6.1 Appraisal of Quantitative studies

Quantitative studies selected were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument from the Joanna Briggs Institute Meta Analysis of Statistics Assessment and Review Instrument (JBI-MAStARI) (http://www.jbiconnect.org/connect/info/about/jbi_ebhc_approach.php). Refer to **appendix H** for the appraisal instrument.

3A.3.6.2 Appraisal of Qualitative studies

Qualitative studies selected for retrieval were assessed by two independent reviewers for methodological validity prior to inclusion in the review using the standardized critical appraisal instrument by Paterson, Thorne & Canam et al. (2001). Refer to **appendix I** for the appraisal instrument.

3A.3.7 Data synthesis

According to Hemingway and Brereton (2009), data synthesis involves collating and summarizing the results of the included primary studies whereby meta-synthesis is conducted if the systematic review inspects qualitative data and meta-analysis is conducted if homogenous quantitative evidence is assessed for clinical effectiveness. On the other hand, if quantitative data are not homogenous then narratives or descriptions are used to summarize the results (Hemingway & Brereton, 2009; Cooper, 2010).

In this study, heterogeneity of the design, population, setting, presence of an intervention and perspectives precluded meta-analytic techniques to statistically combine data. The findings were therefore, summarized and then a detailed qualitative description of included studies was done.

Following a method advocated by Harden (2010) the qualitative and quantitative studies were integrated using thematic analysis. In this stage, the researcher read through all the findings and conclusions of the articles. Once an understanding of the findings was sought, an initial coding was done. This was followed by collapsing codes and developing descriptive themes

with more explanatory and analytical themes developed later. These themes were grouped into three groups (factors that enable or complicate EOL care, patients'/family members'/nurses' experiences, attitudes, beliefs, feelings and perceptions of EOL care and decision making processes) as discussed in section (3A.9) Thereafter, the researcher came up with recommendations from these themes that were integrated with those from steps 3 and 4 and reflected evidence for EOL care guideline development (refer to **table 4.2**).

3A.3.8 Validity and reliability

The following measures were instituted in order to ensure validity and reliability of the systematic review:

- The process of conducting systematic review was applied as described by Dicenso et al. (2005:140). Stringent measures of validity were implemented so as to ensure representativeness of the literature sources used.
- All literature was appraised prior to inclusion in the systematic review.
- Bias in the study was reduced by use of multiple electronic databases for literature retrieval. Journal hand searches and reference lists of relevant articles was also used to retrieve literature.
- Reliability was maintained by ensuring consistency in the selection of literature by adherence to predetermined inclusion criteria
- A co-reviewer was involved during systematic review so as to ensure accuracy and reliability of selected information. The co-reviewer is a registered JBI assessor of both qualitative and quantitative reviews, recognized internationally as an expert in critical care nursing and an experienced researcher. Her main role was to assist in the process of co-coding of the included studies in the systematic review.

3A.4 SELECTION OF INCLUDED STUDIES

Figure 3A.2 shows the steps (Moher, Liberati & Tetzlaff et al., 2009) used to select the final 23 studies for this study. In the **initial phase**, the search yielded 4389 titles of potentially relevant citations which were screened for retrieval (Scopus (n=1697); Science direct (n=1428); Pub med (n=126); Cochrane (n=12); Medline (n=1018); CINHAL (n=89) and 19

articles (n=19) were derived from hand searched references). Of these titles, 4281 were excluded on the basis of **title review** (not applicable based on eligibility criteria).

In the **next phase**, the remaining (n=108) titles were retrieved for evaluation of abstracts. Fifty eight (n=58) were excluded based on **abstract review** because 34 (n=34) were related to a hospice patient population, five (n=5) were related to a pediatric patient population, eight (n=8) were concerned with an old age home population and 11 (n=11) were deemed to be related to other hospital/ward population. Thus 50 articles (n=50) were retrieved for **evaluation of the full text**.

In the **third phase**, 27 titles were excluded based on a detailed evaluation of full text; 11 (n=11) had no original report, three (n=3) were duplicate copies, eight (n=8) were non ICU population and five (n=5) did not fulfil basic criteria for a study. The final selection included 23 (n=23) full text articles which were selected based on them focusing on EOL care issues in the adult ICUs.

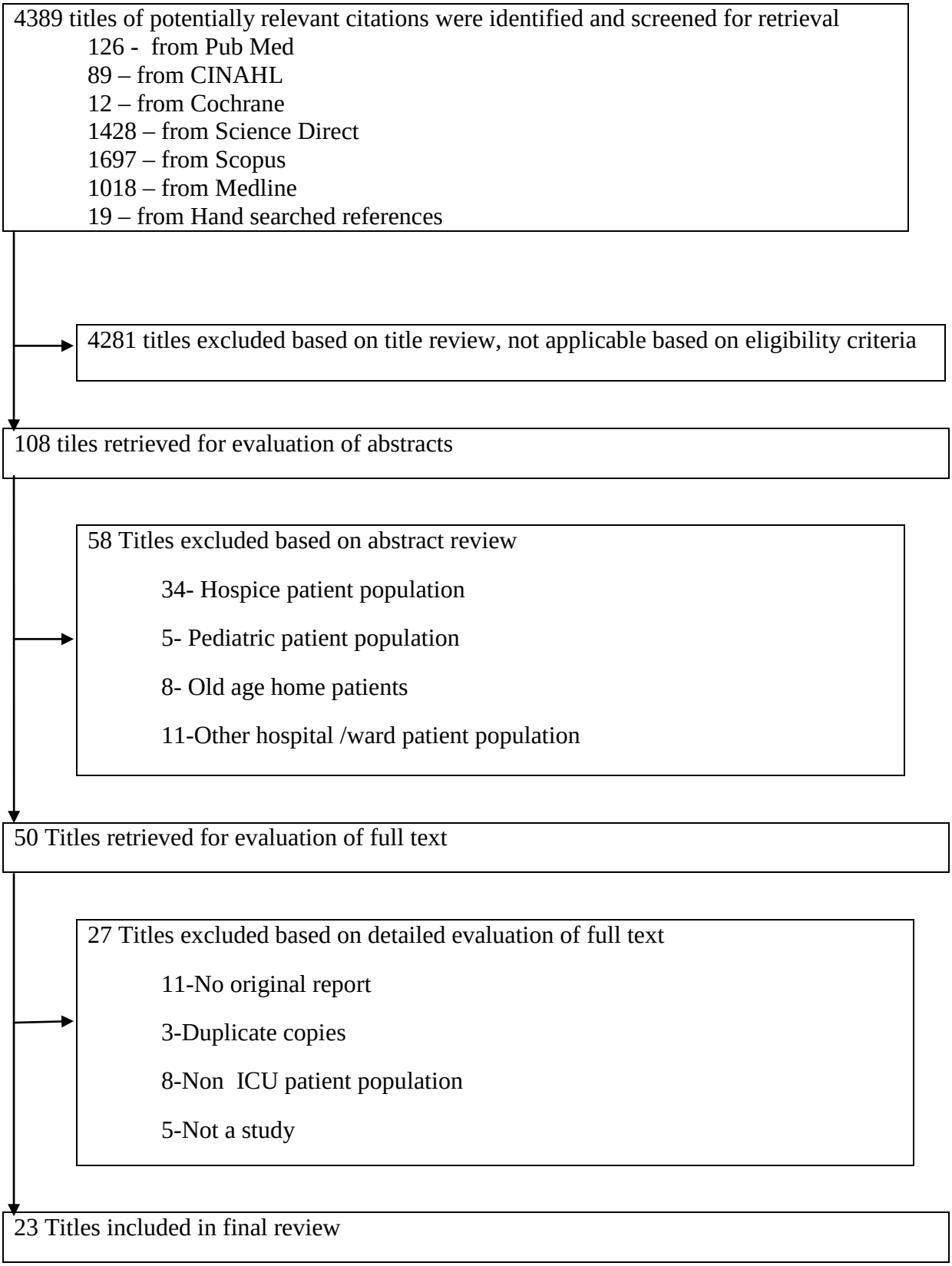


Figure 3A.2 Flow diagram of the selection process for articles used in the study

3A.5 LIST OF INCLUDED STUDIES IN THE FINAL REVIEW

In total, 23 articles were selected and included in the final review. **Table 3A.1** presents the list including a full description of each article.

Table 3A.1 List of included studies in the final review

Author (Year)	Country	Title	Journal name	Volume, issue, page
Badger (2005a)	USA	Factors that enable or complicate end-of-life transitions in critical care	American journal of critical care	14: 513-521
Badger (2005b)	USA	A descriptive study of coping strategies used by medical intensive care unit nurses during transition from cure to comfort-oriented care	Heart & Lung	34(1):63-68
Beckstrand, Callister and Kirchhoff (2006)	USA	Providing a "Good death": Critical care nurses' suggestions for improving end-of-life care	American journal of critical care	15(1):38-45
Hov, Hedelin and Athlin (2007a)	Norway	Good nursing care to ICU patients on the edge of life	Intensive and critical care nursing	23:331-341
Hov, Hedelin and Athlin (2007b)	Norway	Being an intensive care nurse related to questions of withholding or withdrawing curative treatment	Journal of clinical nursing	16(1):203-211
McMillen (2008)	England	End of life decisions: Nurses perceptions, feelings and experiences	Intensive and critical care nursing	24:251-259
Calvin, Lindy and Clingon (2009)	USA	The cardiovascular intensive care unit nurse's experience with end-of-life care: A qualitative descriptive study	Intensive and critical care nursing	25:214-220
Fridh, Forsberg and Bergbom (2009a)	Sweden	Doing one's utmost: descriptions of caring for dying patients in an intensive care environment	Intensive and critical care nursing	25:233-241
Fridh, Forsberg and Bergbom (2009b)	Sweden	Close relatives' experiences of caring and of the physical environment when a loved one dies in an ICU	Intensive and critical care nursing	25:111-119
Zomorodi and Lynn (2010a)	USA	Critical care nurses' values and behaviours with end-of-life care	Journal of hospice and palliative nursing	12(2):89-96

Lind, Lorem, Nortvedt, et al. (2011)	Norway	Family members' experiences of "wait and see" as a communication strategy in end-of-life decisions	Intensive care Medicine	37:1143-1150
Heyland, Rocker, O'Callaghan, et al. (2003)	Canada	Dying in the ICU: Perspectives of family members	CHEST	124:392-397
Beckstrand and Kirchoff (2005)	USA	Providing End-of-Life care to patients: Critical care nurses' perceived obstacles and supportive behaviours	American Journal of critical care	14:395-403.
Cohen, Sprung, Sjokvist, et al. (2005)	Europe	Communication of end-of-life decisions in European intensive care units	Intensive care medicine	31:1215-1221
Ho, English and Bell (2005)	New Zealand	The involvement of intensive care nurses in end-of-life decisions: a nationwide survey	Intensive care Medicine	31:668-673
Kjerulf, Regehr, Popova, et al. (2005)	Canada	Family perceptions of end-of-life care in an urban ICU	CACCN	16(3):22-25
Benbenishty, Ganz, Lippert, et al. (2006)	Europe	Nurse involvement in end-of-life decision making: the ETHICUS study	Intensive care medicine	32:129-132
Gries, Curtis, Wall, et al. (2008)	USA	Family member satisfaction with end-of-life decision making in the ICU	CHEST	133:704-712
Hansen, Goodell, DeHaven, et al. (2009)	USA	Nurses' perceptions of end-of-life care after multiple interventions for improvement	American journal of critical care	18(3):263-271
Latour, Fulbrook and Albaran (2009)	Europe	EfCCNa survey: European intensive care nurses' attitudes and beliefs towards end-of-life care	Nursing in critical care	14(3):110-121
Bloomer, Tiruvoipati, Tsiripillis, et al. (2010)	Australia	End of life management of adult patients in an Australian metropolitan intensive care unit: A retrospective observational study	Australian critical care	23(1):13-19
Crump, Schaffer and Schulte (2010)	USA	Critical care nurses' perceptions of obstacles, and knowledge needed in providing quality end of life care	Dimensions of critical care nursing	29(6):297-306
Labram and Hughes (2010)	Scotland	End-of-life care in Scottish intensive care units	Journal of intensive care society	11(4):245-249

3A.6 METHODOLOGICAL QUALITY ASSESSMENT OF THE SELECTED STUDIES

The study articles (n=23) were reviewed by the researcher with support from a co-reviewer. In order to improve the appraisal process, as recommended by Cooper (2010), two reviewers independently extracted and appraised details of selected articles using standardized forms **(appendix G, H** and **I)** and resolved discrepancies by consensus. As suggested by Kitchenham (2004), once the primary studies had been selected, a more detailed quality assessment needed to be made because this allows a researcher to assess the quality of the studies to include in the final review. Detailed quality assessments are usually based on "quality instruments" which are checklists of factors that need to be assessed for each study and, if quality items within a checklist are assigned numerical scales, numerical assessments of quality can be obtained (Kitchenham, 2004).

In this review, a set of criteria derived from checklists by Paterson, Thorne, & Canam, et al. (2001) and Joanna Briggs Institute (JBI) (http://www.jbiconnect.org/connect/info/about/jbi_ebhc_approach.php) was used to assess the methodological quality of included studies. The checklists graded the quality of studies from 0 to a maximum of 2. For all the studies, each item on the checklist was scored 0 (not stated), 1 (not explicitly stated) and 2 (clearly stated). Numbers of scores were calculated for each study and converted into percentages (refer to **tables 3A.2** and **3A.3** for the results).

Systematic reviews are an important tool for developing clinical recommendations and inclusion of primary studies that are of high quality assure a good level of confidence on the strength of the recommendations (Vigna-Taglianti, Vineis, Liberati, 2006). While there is no set level of the quality score (Kitchenham, 2004; Whiting & Kleijnen, 2005; Cooper, 2010), the minimum quality score was set at 70% in order to ensure that high quality studies were used. This set minimum score was based on the relative importance assigned to different research design characteristics by the two reviewers and agreement as to how well these two reviewers thought a particular study met a particular criterion. Each of the articles met the inclusion criteria as well as attaining the minimum required methodological quality assessment scores.

Table 3A.2 below displays the results of the assessment of methodological quality of included qualitative studies. The methodological items being assessed are from items 1-15 (item 1. aim clearly stated, 2. description of study population, 3. sampling procedure described, 4. description of inclusion criteria, 5. appropriate sample size determined, 6. description of data collection procedure, 7. data analysis methods described, 8. categories identified, 9. analysis supported by illustration, 10. statement about consent provided, 11. permission to undertake the study, 12. discussion pertaining to all significant findings, 13. indication of future research, 14. conclusion provided and 15. Identification of limitations) as shown in **appendix I** (Paterson, et al., 2001).

The scores are from 0 to a maximum of 2, which translates to 0 = not stated, 1 = not explicitly stated 2 = clearly stated. The total scores added up to 30 (100%). The highest score for the included articles was 30 (100%) and the lowest was 25 (83.3%). The minimum score for a study to be considered for this research was set at 70%. With the included qualitative studies scoring between 83.3% and 100%, it is evident that the studies included in the review were of a high quality.

Table 3A.2 Results of methodological assessment of qualitative studies (n=11)

Author	**Methodological items being assessed (items 1-15)**															
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**	**15**	
	Scores per item															**Total scores (%)**
Badger (2005a)	2	2	2	2	2	2	2	2	2	2	2	2	0	2	2	28 (93.3)
Badger (2005b)	2	2	2	2	2	2	2	2	2	1	1	2	0	2	2	26 (86.7)
Beckstrand et al. (2006)	2	2	2	1	2	2	1	2	2	1	2	2	2	2	0	25 (83.3)
Hov et al. (2007a)	2	2	2	2	2	2	2	2	2	0	2	2	2	2	2	28 (93.3)
Hov et al. (2007b)	2	2	2	2	2	2	2	2	2	2	2	2	2	2	0	28 (93.3)
McMillen (2008)	2	2	2	2	2	2	2	2	2	2	2	2	2	2	0	28 (93.3)
Calvin et al. (2009)	2	2	2	2	2	2	2	2	2	2	2	2	2	2	0	28 (93.3)
Fridh et al. (2009a)	2	2	2	2	2	2	2	2	2	2	2	2	0	2	0	26 (86.7)
Fridh et al. (2009b)	2	2	2	2	2	2	2	2	2	2	2	2	0	2	0	26 (86.7)
Zomorodi and Lynn (2010a)	2	2	2	2	2	2	2	2	2	2	2	2	2	2	2	30 (100)
Lind et al. (2011)	2	2	2	2	2	2	2	2	2	2	2	2	0	2	2	28 (93.3)

Table 3A.3 below shows the results of the assessment of methodological quality of included quantitative studies. The methodological items being assessed are from items 1-12 (item 1. Does it clarify what was studied? 2. Is it clear how the samples were obtained? 3. Are the aims clearly stated? 4. Is the design appropriate to the stated objectives? 5. Are the measurements valid and reliable? 6. Are the statistical methods adequately described? 7. Was the statistical significance assessed? 8. Is the meaning of the main findings clear? 9. Can results be generalized? 10. Do results compare with other reports? 11. Are all researchers' names and qualifications present? and 12. Are researchers' contact details present?) as displayed in **appendix H** (http://www.jbiconnect.org/connect/info/about/jbi_ebhc_approach.php).

The scores recorded are from 0 to a maximum of 2, which translates to 0 = not stated, 1 = not explicitly stated 2 = clearly stated. Total scores added up to 24 (100%). The minimum score set for this study was 70%. The scores obtained ranged from (19) 79.2% to (24) 100% indicating that the selected studies were of high quality.

Table 3A.3 Results of methodological assessment of quantitative studies (n=12)

Author	**Methodological items being assessed (items 1-12)**												
	1	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	
	Scores per item												**Total scores (%)**
Heyland et al. (2003)	2	2	2	2	2	2	1	2	2	2	2	2	23 (95.8)
Bekstrand & Kirchoff (2005)	2	2	2	2	2	2	2	2	1	2	2	1	22 (91.7)
Cohen et al. (2005)	2	1	2	2	2	2	2	2	1	2	1	1	20 (83.3)
Ho et al. (2005)	2	2	2	2	2	2	2	2	0	2	1	2	21 (87.5)
Kjerulf et al. (2005)	2	2	2	2	1	2	1	2	2	2	2	0	20 (83.3)
Benbenishty et al. (2006)	2	2	2	2	2	2	2	2	1	2	1	1	21 (87.5)
Gries et al. (2008)	2	2	2	2	2	2	2	2	1	2	2	2	23 (95.8)
Hansen et al. (2009)	2	0	2	2	2	2	2	2	2	2	2	2	22 (91.7)
Latour et al (2009)	2	2	2	2	2	2	2	2	2	2	2	2	24 (100)
Bloomer et al. (2010)	2	2	2	2	2	0	0	2	1	2	2	2	19 (79.2)
Crump et al. (2010)	2	2	2	2	2	2	2	2	2	2	2	2	24 (100)
Labram and Hughes (2010)	2	0	2	2	2	1	1	2	2	2	2	2	20 (83.3)

3A.7 CHARACTERISTICS OF INCLUDED STUDIES

Out of the selected 23 (n=23) studies, only one (n=1) was dated 2003, six (n=6) were dated 2005, two (n=2) were dated 2006 and 2007 respectively. Two (n=2) were dated 2008, five (n=5) studies were dated 2009 followed by four (n=4) dated 2010 and one (n=1) dated 2011. Most of the studies were conducted in Europe (n=10) followed by USA (n=9) with the rest from Canada (n=2), Australia (n=1) and New Zealand (1).

With respect to the methodology, the sample consisted of both quantitative (n=12) and qualitative (n=11) studies. Quantitative studies used survey questionnaires, observations and chart audits whereas qualitative studies used focus group interviews, individual interviews, combined survey and open ended questions/suggestions and retrospective audits as data collection methods. The sample sizes in the questionnaire (survey) studies ranged from 70 to 4248 participants and the response rates was between 31% to 81% whereas the sample size in qualitative studies ranged from 9 to 27 participants as shown in **table 3A.4**.

3A.8 RESULTS OF INCLUDED STUDIES

Table 3A.4 presents the summary of the results obtained from the primary studies (n=23) included in the systematic review. The first eleven presentations are those of qualitative studies followed by the twelve quantitative studies presented after a shaded row. Immediately after the summary in table format, the results are discussed in greater detail for clarity.

Table 3A.4 Summary of the results of studies (n=23) included in the systematic review

Author and Year	Phenomenon investigated and (main findings)	Method, previously tested instrument (if used), sample size, response rate (if reported), location
Badger (2005a)	**Enabling and complicating factors in EOL transitions**: (patient's age, misunderstanding of illness by family, family discord and shifting medical care decisions made complicated transitions whereas developing consensus about direction of care, exhausting treatment and patient's lack of response to aggressive interventions helped nurses move to comfort care).	➢ Descriptive phenomenology ➢ Focus group interviews, observation ➢ 19 female and 5 male nurses ➢ 18-bed MICU in USA
Badger (2005b)	**Coping strategies of nurses during transition from cure to comfort-oriented care**: (Nurses used cognitive, affective and behavioral techniques to cope with EOL transitions).	➢ Descriptive phenomenology ➢ Observation, focus group interviews ➢ 19 female and 5 male nurses ➢ 18-bed MICU in USA
Beckstrand et al. (2006)	**Providing a good death**: (Barriers included: nursing time constraints, communication challenges, staffing patterns, treatment decisions based on physician's rather than patient's needs. Enabling factors included: dying with dignity, no patient should die while alone, managing patient's pain/discomfort, following patient's wishes, promoting earlier cessation of treatment, effective communication and educational initiatives).	➢ Survey ➢ Questionnaire ➢ Sample n=1409 nurses ➢ Response rate 61% ➢ USA
Hov et al. (2007a)	**Good nursing care to ICU patients on the edge of life**: (This depended on: continuity, knowledge, competence, cooperation, nurses' verbal communication and use of hands).	➢ Interpretive phenomenology ➢ Focus group interviews ➢ 14 female nurses ➢ 9-bed ICU in Norway
Hov et al. (2007b)	**Being an intensive care nurse in situations related to questions of withdrawing and withholding curative treatment**: (Loneliness in responsibility, alteration between optimism and pessimism, uncertainty, being a critical interpreter and a dedicated helper).	➢ Interpretive phenomenology ➢ Focus group interviews ➢ n=14 female nurses ➢ 9-bed ICU in Norway
McMillen (2008)	**Nurses' perceptions, feelings and experiences of EOL decisions**: (Experience counts, not really a nurse's decision, planting the seed, supporting the family, being patient advocate, getting the timing right	➢ Constructivist grounded theory ➢ Semi-structured interviews ➢ n=8 nurses

	and emotional labor).	➢ England
Calvin et al. (2009)	**Nurses' experiences of EOL care:** (Exhausting patient treatments, promoting family presence, acknowledging physician authority and walking a fine line).	➢ Descriptive phenomenology ➢ Individual interviews ➢ 19 nurses ➢ 51-bed CVICU in USA
Fridh et al. (2009a)	**Nurses' experiences and perceptions of caring for dying patients/unaccompanied patients**: (Doing one's utmost, dignified EOL care).	➢ Descriptive phenomenology ➢ Individual interviews ➢ 9 nurses ➢ 3 ICUs in Sweden
Fridh et al. (2009b)	**Close relatives' experiences of caring and physical environment when a loved one dies in ICU**: (Being confronted with threat of loss, maintaining a vigil, trusting the care, adapting and trying to understand, facing death, privacy and togetherness and reconciliation).	➢ Descriptive phenomenology ➢ Interviews ➢ n=17 relatives ➢ 3 ICUs in Sweden
Zomorodi and Lynn (2010a)	**Critical care nurses' values and behaviours with EOL care**: (Nurses used "balancing", "trial and error", "coaching the physicians" and "taking a step back" as strategies to improve the quality of EOL care).	➢ Descriptive phenomenology ➢ Semi-structured interviews ➢ n=9 nurses ➢ USA
Lind et al. (2011)	**Family members' experiences of EOL decision making process**: (Relatives want a more active role in EOL decision making but they find their role to be unclear, "wait and see" hides and delays communication of honest and clear information, nurses should be more involved in family physician communication).	➢ Constructivist interpretive approach to grounded theory ➢ Interviews ➢ n=27 family members ➢ Norway
Heyland et al. (2003)	**Perspectives of family members to the care of critically ill patients who died in the ICU**: (Adequate communication, good decision making, respect and compassion for patients and families lead to family satisfaction).	➢ multicenter, prospective, observational study ➢ Survey questionnaire ➢ n=256 family members ➢ Response rate=62% ➢ Canada

Beckstrand and Kirchoff (2005)	**Nurses' perceived obstacles and supportive behaviors in EOL care**: (Obstacles include: behaviors of families that remove nurses from caring for patients, behaviors that prolong patient's pain or suffering and physicians' disagreement about the plan of care. Supportive behaviors included: allowing family adequate time alone with patient, providing dignified death).	➢ Experimental posttest only control group design ➢ Survey questionnaire ➢ Sample n=864 nurses (92.4% female; 6.6% male) ➢ Response rate 61.3% ➢ USA
Cohen et al. (2005)	**Communication of EOL decisions**: (There was high level of discussions between nurses and physicians, patients lacked decision making capacity at the time of EOL decision, families were more often told than asked about EOL decisions because the physician believed that the family would not understand).	➢ Prospective observational study ➢ Questionnaire ➢ n=4248 patients in 37 ICUs ➢ 17 European countries
Ho et al. (2005)	**Involvement of ICU nurses in EOL decisions**: (most ICU nurses especially senior nurses were often involved in EOL decisions).	➢ Survey ➢ Questionnaire ➢ n=611 nurses in 35 ICUs ➢ Response rate estimated between 43% and 81% ➢ New Zealand
Kjerulf et al. (2005)	**Family perception of EOL care in ICU**: (Being informed of any changes, continuity, one individual acting as family contact, questions to be answered and to be present when the patient died).	➢ Survey ➢ Questionnaire ➢ n=51 next of kin ➢ Response rate 34% ➢ Canada
Benbenishty et al. (2006)	**Nurse involvement in EOL decision making**: (Nurses are involved to a large extent in EOL decisions but not as initiating the discussion).	➢ Prospective observational study ➢ Questionnaire ➢ n=3086 patients admitted to 37 ICUs ➢ 17 European countries
Gries et al. (2008)	**Family members' satisfaction with EOL decision making**: (This is associated with palliative care indicators such as physician recommendations to withdraw life support, expression of patient's wishes and discussion of families' spiritual needs).	➢ Cohort study ➢ Questionnaire and chart ➢ n=356 families ➢ Response rate, 41.2% ➢ Seattle-Tacoma (USA)

Hansen et al. (2009)	**Nurses' perceptions of EOL care after multiple interventions for improvement**: (nurses may lack knowledge and skills in EOL care, find caring for dying patients and their families stressful and lack support to provide this care).	➢ Survey ➢ Questionnaire ➢ Phase I=91 nurses (34% response rate) ➢ Phase II=127 nurses (47% response rate) ➢ USA
Latour et al. (2009)	**Nurses' attitudes and beliefs towards EOL care**: (most nurses indicated direct involvement in EOL patient care, active involvement in decision making process, commitment to family involvement in EOL decisions, decreasing the flow of inspired oxygen, providing continuous pain relief, endorsing open visiting and not transferring the patient to a single room. Division of views occurred on deeply sedating and continuing patient's nutritional support).	➢ Survey ➢ Questionnaire ➢ n=419 delegates attending conference in Europe ➢ Response rate 39%
Bloomer et al. (2010)	**End of life management review process and family involvement**: (death in the ICU was often predictable and EOL care management was a consultative approach with most families being present for discussions and at the time of death).	➢ Retrospective observational study ➢ Chart audit ➢ n=70 patients ➢ 70 charts reviewed ➢ Australia
Crump et al. (2010)	**Nurses' perceptions of obstacles, supports and knowledge needed in providing EOL care**: (Families and patients need clear, direct and consistent information to make EOL decisions, physician related issues affect nurses' ability to provide quality EOL care, nurses need more knowledge, skill and sense of cultural competency to provide quality care and having properly completed advance directives can reduce confusion about the goals of care).	➢ Survey ➢ Questionnaire ➢ Sample n=56 (87.5% female; 12.5% male nurses) ➢ Response rare 31% ➢ USA
Labram and Hughes (2010)	**Nurses' attitudes and change towards EOL care**: (suggestions for improvement were: monitor alarms should be turned off, symptom relief for comfort, care of relatives, religious support, family being more often involved in decision making and direct care of their loved one).	➢ Survey ➢ Questionnaire ➢ Sample n= 571 nurses (in 23 ICUs) ➢ Response rate 62% ➢ Scotland

The following section presents the discussion of the results of both qualitative and quantitative studies included in the systematic review (n=23) in a greater detail.

3A.8.1 Presentation of the results of Qualitative studies (n=11)

To begin with, Badger (2005a) explored nurses' experiences of moving from cure to comfort-oriented care and described factors that inhibit or facilitate such transitions. A descriptive phenomenological approach with brief observation of participants and focus group interviews was used. Participants included nineteen female and five male nurses in an eighteen-bed medical ICU at Rhode Island Hospital in the North-Eastern United States.

Findings from Badger's (2005a) study indicated that the transition point between cure and comfort oriented care was unclear. Nurses reported that the patient's age, misunderstanding of the illness by patient's family, family discord and shifting medical care decisions as factors that made EOL care transitions difficult. On the other hand, developing consensus among patients, patients' families and staff about the direction of medical therapy, exhausting treatment options and patients' lack of responses to aggressive medical interventions helped nurses to move toward comfort care. The author concluded that the most important factor was developing consensus about the treatment.

In another study, Badger (2005b) explored nurses' coping behaviours while caring for patients whose medical treatment transitioned from cure to comfort oriented care using a descriptive phenomenological approach. Brief selective participant observation and focus group interviews were used to explore the coping experiences of medical ICU nurses in an 18-bed medical ICU located in North-Eastern United States.

His findings indicated that nurses used a variety of cognitive (learning from experience, visualizing, reminiscing and putting things into perspective), affective (laughter, externalizing feelings and emotionally compartmentalizing) and behavioural (retreating, avoiding and distancing behaviours) techniques to cope with EOL transitions. Study participants reported that being a medical ICU nurse in itself provided a sense of pride for most staff because most

of them believed that their clinical opinions were valued and that they were respected as professionals. Providing futile care, the perceptions of “torturing the patient” and conflict with families caused the greatest distress for staff. The author concluded that nurses are dynamic and resourceful when responding to challenging EOL patient care situations.

On the other hand, Beckstrand et al. (2006) conducted a survey to collect suggestions from critical care nurses for improving EOL care in ICUs. Survey questionnaires were sent to a geographically dispersed random sample of 1409 members of the American Association of Critical-Care Nurses in the USA. Of the 861 critical care nurses who responded to the survey (a response rate of 61%), 485 offered 530 suggestions for improving EOL care.

These suggestions were coded and synthesized by the researchers and providing a “good death” was a major theme: specific suggestions included ways to help ensure death with dignity and peace. Barriers to providing good death included nursing time, constraints, staffing patterns, communication challenges, and treatment decisions that were based on physician rather than patient needs.

Suggestions for improving a good death as found out by Beckstrand et al. (2006) included dying with dignity by not allowing the patient to be alone while dying, managing patient’s pain and discomfort, knowing and then following through patient’s wishes for EOL care; promoting earlier cessation of treatment and not initiating aggressive treatment at all; and communicating effectively as a health care team. Educational initiatives for professionals and public were also suggested. The author concluded that implementation of specific suggestions provided by experienced nurses might increase the quality of EOL care facilitating a good death for intensive care patients.

Hov et al. (2007a) conducted a study using ICU nurses’ experiences with the aim of acquiring a deepened understanding of what good nursing care is for these patients. The study was performed in a 9-bed adult ICU in Norway, where 14 ICU female nurses were included as participants. The research approach was interpretive phenomenology and data were collected

by means of group interviews. Participants were divided into two groups and each group was interviewed four times.

The findings showed that good nursing care depended on several basic conditions including: continuity in nursing care, nurses' knowledge, nurses' competence and cooperation and included clear goals to give appropriate life-saving suggestions on EOL treatment and care. Cornerstones in good nursing care were nurses' verbal communication to reduce patients' confusion and nurses' use of their hands, focusing on patients' object-subject bodies.

The aim of an interpretive phenomenological study conducted by Hov et al. (2007b) was to acquire a deeper understanding of what it is to be an intensive care nurse in situations related to withholding or withdrawing curative treatment. To achieve this, the authors conducted group interviews with 14 critical care nurses in an adult 9-bed ICU in Norway. Participants were divided into two groups and each group was interviewed four times. The analysis revealed 4 themes including: loneliness in responsibility, alteration between optimism and pessimism, uncertainty which is a constant shadow and professional pride despite little formal influence. The essence of being an intensive care nurse in the care of patients when questions were raised concerning curative treatment or not, was understood as 'being a critical interpreter and a dedicated helper'. The findings underpin the important role of intensive care nurses in providing care and treatment to patients related to questions of withholding and withdrawing curative treatment.

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In her study, McMillen (2008) used a constructivist grounded theory to explore the experiences of ICU nurses caring for patients who have had their treatment withdrawn. Semi structured interviews were used to collect data on 8 ICU nurses from one ICU in the north of England. The analysis resulted in two major themes including: the nurses role (experience counts, not really a nurse's decision, planting the seed, supporting the family and being a patient advocate), and perceptions of the withdrawal of treatment (getting the timing right and emotional labor). The conclusion of the study was that nurses make an important contribution to EOL decisions and care, therefore it is imperative that nurses are supported in this role and their responsibilities to continue to provide care during withdrawal.

Calvin et al. (2009) conducted a descriptive phenomenological study to explore nurses' informally expressed moral angst when caring for patients who are approaching the EOL. Nineteen nurses from one 51-bed cardiovascular intensive care unit in the USA were interviewed individually regarding their experiences when caring for patients approaching the end of life, and specifically initiating the change in code status (transition). Findings revealed four major themes including: exhausting patient treatments, promoting family presence at EOL, acknowledging physician authority in discussion and decision making and walking a fine line. The authors concluded that the results of the study provide a basis for putting in place support systems for ICU nurses.

Fridh et al. (2009a) carried out a descriptive phenomenological study to explore the nurses' experiences and perceptions of caring for the dying patients in the ICU with the focus on unaccompanied patients, the proximity of family members and environmental aspects. Interviews were conducted with 9 experienced intensive care nurses working in three Swedish ICUs. Findings resulted in one main category: Doing one's utmost, described by four generic categories and 15 sub-categories, comprising a common vision of patient's last hours and dying process. This description was dominated by the nurses' endeavour to provide dignified EOL care and, when relatives were present, to give them an enduring memory of their loved one's death as a calm and dignified event despite their suffering in a high technological environment.

Fridh et al. (2009a) concluded that their study contributes new knowledge about what ICU nurses' focus on when providing EOL care to unaccompanied patients but also to those whose relatives were present. Nurses' EOL care was mainly described as their relationship and interaction with the dying patients' relatives, while patients who died alone were considered tragic but left a lesser impression in the nurses' memory.

A descriptive phenomenological study was carried out by Fridh et al. (2009b) to explore close relatives' experiences of caring and the physical environment when a loved one died in the ICU. Seventeen close relatives of fifteen patients who had died in three ICUs in the Western part of Sweden were interviewed. Seven themes emerged from this study and they

included: being confronted with the threat of loss, maintaining a vigil, trusting the care, adapting and trying to understand, facing death, the need for privacy and togetherness and experiencing reconciliation.

In addition, Fridh et al. (2009b) indicate that the experience of caring relationship was central, which meant that the health care team directed the close relatives' past the 'hidden reefs' and through the 'dark waters' of the strange environment, unfamiliar technology, distressing information and waiting characterized by uncertainty. Not being directed meant not being invited to enter into a caring relationship, not being allowed access to the dying loved one and not being assisted in interpreting information. In conclusion, the relatives experienced the dying loved one's serious condition and his or her dependence on the medical-technical equipment as more frightening than the equipment as such and returning for a follow-up visit provided an opportunity for reconciliation and relief from guilt.

Zomorodi and Lynn (2010a) conducted a descriptive phenomenological study with an aim of exploring nurses' definitions of quality EOL care and to identify factors that facilitate or inhibit the nurses' ability to provide EOL care to patients and their families. Nine critical care nurses from one ICU in the USA were individually interviewed. Nurses reported that several aspects hinder their ability to render quality EOL care including: moral distress, constant noise and technology, lack of time, ambiguity, fragmentation of care and frustration with physicians including communication problems between physicians, nurses, patients and families. Strategies for improving quality EOL care elicited from the participants included: ensuring adequate communication and confronting the relational ambiguity.

Finally under the qualitative studies reviewed, a study to examine family members' experiences of EOL decision making process to ascertain the degree to which they felt included and whether they received necessary information was conducted by Lind et al. (2011). A constructivist interpretive approach to grounded theory was employed with interviews of 27 family members of former 21 ICU patients. General ICUs that had more than eight beds in three University hospitals and one district hospital in Norway were selected.

The study revealed that relatives want a more active role in EOL decision making in order to communicate the patient's wishes. However, many consider their role to be unclear, and few study participants experienced shared decision making. It was reported that the clinician's expression of "wait and see" hides and delays the communication of honest and clear information and that when physicians finally address their decisions, there is no time for family participation. The results also indicated that nurses should be more involved in family-physician communication and contribute to building a team for family support.

3A.8.2 Presentation of the results of Quantitative studies (n=12)

To start with, Heyland et al. (2003) conducted a multicenter, prospective, observational study to describe the perspectives of family members to the care provided to critically ill patients who died in the ICU. The study was conducted in six university-affiliated ICUs across Canada which admitted both surgical and medical patients and had eight to twenty four beds. Patients who received mechanical ventilation for > 48 hours and who died in the ICU were included in the study. Three to four weeks after the patient's death, questionnaires were emailed to one selected family member of 413 eligible non surviving ICU patients. A total of 256 family members completed the survey (response rate of 62%). The results indicated that most family members (90.4%) preferred some form of shared decision making, 52% of them rated their satisfaction with care as excellent. Fifty seven percent of them felt very supported by the health care team and 34.8% believed that the patients were totally comfortable in their final hours before death.

Overall satisfaction with EOL care as stated by Heyland et al. (2003) was significantly associated with completeness of information received by the family members and satisfaction with amount or level of health care received. In conclusion, the authors stated that adequate communication, good decision making, and respect and compassion shown to both the dying patient and their family are key determinants to family satisfaction.

Bekstrand and Kirchoff (2005) conducted a study to measure nurses' perceptions of the intensity and frequency of obstacles to providing EOL care and supportive behaviours that help nurses in providing EOL care. The methods used in this study involved an experimental

post-test only and a control group design. A national, geographically dispersed, random sample of members of the American Association of Critical-Care nurses in the USA were surveyed. The response rate was 61.3%; 864 useable responses were obtained from 1409 eligible respondents. The highest scoring obstacles were frequent telephone calls from patients' families for information, families who did not understand the term lifesaving measures and physicians disagreeing about the direction of a dying patient's care.

On the other hand, the highest scoring supportive behaviours as stated by Bekstrand and Kirchoff (2005) were allowing families adequate time alone with patients after death, providing a peaceful and dignified bed side scenes, and teaching patients' families how to act around a dying patient. The authors concluded that the biggest obstacle to appropriate EOL care in ICU are behaviours of families, such as frequent telephone calls that remove nurses from caring for patients, behaviours that prolong patient's suffering or pain such as families not accepting a patient's poor prognosis and wanting life sustaining measures to be continued and physician's disagreement about the plan of care.

In order to examine EOL practices in European ICUs on who makes these decisions, how they are made, communication of these decisions between physicians, nurses, patients and families, Cohen et al. (2005) conducted a prospective observational study of EOL decisions in 4,248 consecutive patients with any limitation of life-sustaining treatment or dying in 37 ICUs in 17 European countries.

Their findings revealed a relatively high level of discussions between nurses and physicians (78%), but this was reported by physicians, and nurses may have responded differently. Ninety five percent of the patients lacked decision making capacity at the time of EOL decision and patient's wishes were known in only 20% of the cases. EOL decisions were discussed with the family in 68% of the cases and the families were more often told (88%) than asked (38%) about EOL decisions. Discussions did not occur with families in many cases because the patient was unresponsive to maximal therapy or because the physician believed that the family would not understand.

In their study, Ho et al. (2005) conducted a survey on 611 ICU nurses in 35 ICUs in New Zealand to investigate the prevalence of and predictors of intensive care nurses' involvement in EOL decisions. The response rate was estimated to be between 43% and 81%. Seventy eight percent of respondents reported active involvement in EOL decisions especially the senior nurses because senior nurses have more experience and are naturally likely to be involved. Asian and Pacific Islands' nurses were often less involved than European nurses and this could have been due to cultural differences towards EOL care between different countries. Sixty eight percent preferred more involvement and this preference was associated with the perception that EOL decisions were made too late. Sixty five percent believed their active involvement in EOL decisions would improve nursing job satisfaction.

Kjerulf et al. (2005) conducted a survey study to determine family perceptions of EOL care in three adult ICUs in Canada. Fifty one surveys were received from the patients' next of kin who had a loved one die in one of the three ICUs resulting in 34% response rate. The findings in this study revealed that family members wanted nurses and physicians to inform them of any changes, have an opportunity to discuss treatment and have questions answered by nurses and doctors, have the same group of nurses provide care for consistency, have one hospital staff member act as the family contact, have time with the patient in preparation for death, have flexible visitation policies which maximize access between family members, their dying loved one and health care professionals.

Physicians' perceptions of the role of European intensive care nurses in EOL decision making were investigated in a study by Benbenishty et al. (2006) using a prospective observational method. This study was part of a larger study sponsored by the Ethics Section of the European Society of Intensive Care Medicine, the ETHICUS study. The study took place in 37 ICUs in 17 European countries whereby EOL decisions were made on 3,086 patients admitted to the ICUs. In this study, physicians described whether they thought nurses were involved in such decisions, whether nurses initiated such decisions and whether there was agreement between physicians and nurses.

The findings revealed that nurses were involved in 78.3% of the EOL decisions made and initiated the discussion in 2.1% of the cases. A 0.6% disagreement between physicians and nurses in relation to EOL decisions were reported. This study concluded that physicians perceive nurses as involved to a large extent in EOL decisions, but not as initiating the discussion, and once a decision is made there is a sense of agreement.

In their study, Gries et al. (2008) conducted a cohort study to determine patient and family characteristics and chart the documentation of process of care that are associated with increased family satisfaction with EOL decision making for ICU patients. The study was conducted in 10 medical centres in the Seattle-Tacoma area (15-65 bed ICUs). A baseline survey and medical record abstraction data was conducted in these ten hospitals. Surveys were mailed to 1,074 family members 1 to 2 months after the patient's death. Among the 442 family members who returned the surveys (response rate, 41.2%), chart abstraction data were available for 356 patients. The findings revealed that increased family satisfaction with decision making is associated with withdrawing life support, and the documentation of palliative care indicators including the following: physician recommendations to withdraw life support; expression of patient's wishes and discussion of families' spiritual needs.

Hansen et al. (2009) conducted a survey study to describe nurses' perceptions of knowledge and ability, work environment and support for staff, patients and families and stress related to specific work situations in the context of EOL care. Nurses in four ICUs at a university medical centre in the USA reported their perceptions of EOL care by using a 5-subscale tool consisting of 30 items scored on a 4-point Likert scale. The tool was completed by 91 nurses (response rate 34%) in phase I and 127 (response rate 47%) in phase II. The authors claimed that nurses may lack knowledge and skills in EOL care, find caring for dying patients and their families stressful and lack support to provide this care. The authors concluded that continued practice development is needed in EOL care issues.

A study by Latour et al. (2009) examined the involvement of nurses in decision making and extent to which their nursing practice is based on shared beliefs, experiences and attitudes. Using a survey method, delegates (n=419) attending an international critical care conference

in Europe were invited to complete a self-administered questionnaire about their involvement with EOL care practices. A total of 164 questionnaires were completed, yielding to a response rate of 39% with the following findings:

- The majority (91.8%) indicated direct involvement in EOL patient care, while 73.4% reported active involvement in decision making process.
- 78.6% of respondents expressed commitment to family involvement in EOL care decisions, however only 59.3% of the participants said that this was routinely undertaken
- In decisions to withdraw or withhold therapy, 65.1% would decrease the flow of inspired oxygen, 98.8% provide continuous pain relief and 91.3% endorse open visiting.
- The majority (78%) disagreed that a dying patient should be transferred to a single room.
- A division of views was observed in relation to 44% agreeing that patients should be kept deeply sedated and equal numbers contesting the continuation of nutritional support (41.6% versus 42.3%).
- The authors concluded that the involvement of nurses in EOL care decisions is reasonably consistent with many engaged in initiating dialogue with co-workers. In general, views and experiences of EOL care were similar, with the exception of the provision of nutrition and use of sedation.

In their study, Bloomer et al. (2010) conducted a retrospective observational study of all deaths in a 10-bed ICU in Australia over a 12-month period to review the end of life processes and family involvement within their unit. The authors reviewed patient demographics, diagnosis on admission, patient acuity and expectation of death and not for resuscitation status. Discussions with the family, treatments withheld and withdrawn and extubation practices were documented. The presence of family at the time of death, the time of death after withdrawal of therapy and family concerns were recorded.

The findings by Bloomer et al. (2010) indicated that there were 70 patients with mean age of 69 years. Death was expected in 60 patients (86%) and the decision not for resuscitation was documented in 58 cases (85%). Family discussions were held in 63 cases (90%) and treatment was withdrawn in 34 deaths (49%). After withdrawal of therapies, 31 patients (44%) died within 6 hours. Ventilatory support was withdrawn in 24 cases (36%). Family members were present at the time of death in 46 cases (66%). Family concerns were documented about EOL care in only 1 case (1.4%). The authors concluded that the data suggested that death in their ICU was often predictable and EOL management was a consultative approach.

In response to critical care nurses' perceptions of increasing stress and conflict in EOL care situations, Crump et al. (2010) conducted a survey study in the USA to identify the perceived obstacles, supports and knowledge needed to provide quality EOL care. The researchers replicated a study by Beckstrand and Kirchoff (2005) using their national survey of critical care nurses regarding EOL questionnaire. The questionnaire contained 29 obstacle items, 24 supportive behaviour items, 4 open-ended questions 15 demographic questions. Open-ended questions asked respondents to identify missing obstacles and helpful behaviours and one thing they would like changed in EOL care. Perceptions of knowledge needed for providing EOL care survey was based on EOL nursing education consortium critical care training. 56 out of 180 nurses participated in this study (female=87.5%; male=12.5%) yielding a response rate of 31%.

The conclusions drawn by Crump et al. (2010) were as follows:

- Families and patients need clear direct and consistent information to make EOL decisions
- Physician related issues affect nurses' ability to provide quality EOL care
- Critical care nurses need more knowledge, skill and sense of cultural; competency to provide quality care
- Having properly completed advance directives can reduce confusion about the goals of care

Finally, Labram and Hughes (2010) conducted a survey to assess practice staff attitudes and desire for change in the way dying patients were cared for in the ICU. A total of 571 replies were received and analyzed yielding a response rate of 62%.The study included medical doctors and nurses working in 23 ICUs in Scotland. Results indicate that majority (62%) of staff were satisfied with current practice in their ICUs, although even the respondents who were satisfied overall, would significantly change care in some areas. Suggestions for improvement were as follows: a small number would not reduce or stop ventilatory, cardiovascular or renal support.

Other suggestions as by Labram and Hughes (2010) included: monitor alarms should be turned off allowing families to direct their attention to the patient, drugs for symptom relief if used for patient comfort are entirely proper, participants reported the importance of care of relatives, religious support, family being more often involved in decision making and encouraged to be involved in the care of their loved one. Authors concluded that institution of a common care pathway at the EOL would allow each unit to decide on the best practice process to facilitate EOL care and have robust system in place to ensure it is consistently delivered.

3A.9 DISCUSSION

The literature search involved searching the databases of SCOPUS, Science direct, Pub med, Cochrane, Medline and CINHAL (2003-2011) using the search terms: comfort care, end-of-life care, palliative care, intensive/critical care and futile care which yielded a handful of results. In order to provide a deeper understanding of EOL issues, the search was broadened using more familiar terminologies including: good death, decision making and withdrawal and withholding of treatment which all together yielded results as presented above. In addition to electronic and manual searches of peer reviewed and professional journals, a search was also done on books, theses and Government documents.

In terms of the quality of the selected (n=23) studies, the assessment revealed that all studies had scores above 70% which is a cut-off point agreed between the two reviewers in this study. A point worth noting is that most papers are from the year 2005 to 2010. This is

interpreted as a growing awareness of critical care EOL issues. In broadening the search using more familiar words such as decision making and withdrawal of treatment while it provided a deeper understanding of existing information on EOL issues, the bigger number of American (n=9) and European (n=10) studies aided the focus of the search.

The review conducted on EOL or comfort care revealed several results from various authors as summarized in **table 3A.4** above and as presented in detail following the summary. After coding, it was discovered that some results and conclusions drawn by different authors were related, the researcher decided to group such similar issues together as themes so as to enhance the flow of the discussion and clarity of the information. The groups included: factors that enable or complicate EOL care, patients'/family members'/nurses' experiences, attitudes, beliefs, feelings and perceptions of EOL care and decision making processes. These main areas are discussed briefly in the section below.

3A.9.1 Factors that enable or complicate end-of-life care

Factors that enable or complicate EOL care were presented by several authors including Badger (2005a), Badger (2005b), Beckstrand and Kirchoff (2005), Beckstrand et al. (2006), Hov et al. (2007a) and Crump et al. (2010).

As stated by these authors, factors that enable EOL care or good death in the ICU and supportive behaviours towards quality EOL care that helped nurses to move toward comfort care included consensus among patients, patients' families and staff about the direction of medical therapy, exhausting treatment options and patients' lack of responses to aggressive medical interventions. In addition, providing a dignified death, not allowing the patient to be alone while dying, managing patient's pain and discomfort, knowing and then following through patient's wishes for EOL care, promoting earlier cessation of treatment and not initiating aggressive treatment at all, communicating effectively as a health care team, providing clear, direct and consistent information, continuity in nursing care, nurses' knowledge, nurses' competence, cooperation and educational initiatives for professionals and public were also suggested as some of the factors that improve quality of EOL care and promote a good death in the ICU.

As stated by Allen (2010), quality care at the EOL requires a degree of skill, and competence and that health care providers should work together to meet patients' physical, emotional, social, cultural and spiritual needs. He also indicates that quality care at the EOL maximises quality of life through appropriate needs-based care which should be based on the patient and family needs and choices. A study by Thacker (2008) also highlights some of the supports towards practicing EOL care including multidisciplinary teams, effective communication, relationships with the patient, the family, and the nurses' knowledge, beliefs and compassion.

Several barriers or obstacles towards quality EOL care in the ICU exist and have been addressed in a study by Downey, Engelberg and Shannon et al. (2006). The barriers identified in this review included misunderstanding of the illness by patient's family, family discord and shifting medical care decisions, providing futile care, limited nursing time, constraints, rigid staffing patterns, communication challenges, treatment decisions that were based on physician rather than patient needs, behaviours of families that remove nurses from caring for patients such as frequent phone calls, behaviours that prolong patient' suffering or pain, physician's disagreement about the plan of care and lack of nurses' knowledge, skills and sense of cultural competency to provide quality EOL care.

3A.9.2 Experiences, attitudes, beliefs, feelings and perceptions of end-of-life care

Nurses', patients' and family members' experiences, attitudes, beliefs, feelings and perceptions of EOL care were investigated by various authors including Heyland et al. (2003), Kjerulf et al. (2005), Calvin et al. (2009), Fridh et al. (2009a), Fridh et al. (2009b), Hansen et al. (2009), Latour et al. (2009), Bloomer et al. (2010), Crump et al. (2010) and Zomorodi and Lynn (2010).

These reviews revealed that majority of the ICU nurses have direct involvement in EOL patient care. Nurses' experiences, attitudes, feelings, perceptions and beliefs towards EOL care were reported. To begin with, doing one's utmost, was dominated by the nurses' endeavour to provide dignified EOL care and, when relatives were present, to offer them support during their time of grieve. It was considered tragic when a patient died without the presence of a family member and in such cases, nurses provided warm and compassionate

care to the unaccompanied patients by never leaving them alone during the dying process. The importance of nursing presence during the dying process has been supported elsewhere by Finfgeld-Connett (2006) and Ott (2010).

Frustration with physicians and communication problems between physicians, nurses, patients and families was also expressed by nurses in these reviews as contributors to their dissatisfaction. Nurses reported that physician authority in discussion and decision making was acknowledged and that even though providing information to the patients is something that nurses know they should do, they expressed reluctance to do so fearing reprimand by the physician. Nurses expressed the need for physicians to speak frankly with family members so as to promote family satisfaction and avoid family distress during EOL care. In order to achieve quality EOL care, Gristina, Gaudio, Mazzon & Curtis (2011:912) in their study pointed out that open lines of communication must be established early and actively cultivated.

During their caring process, nurses also stated that they may lack knowledge and skills in EOL care, find caring for dying patients and their families stressful and lack support to provide this care. A study by Ott (2010) supports these authors concerning the lack of knowledge and skills. He states that evidence from major studies has repeatedly demonstrated that both nurses and physicians lack a solid understanding of a good EOL care. Apart from this, participants reported the importance of care of relatives, religious support, ensuring patient's symptom control and comfort measures (such as pain control, hygiene, positioning and suctioning) family being more often involved in decision making and encouraged to be involved in the care of their loved one as these contributed partly to their satisfaction of care rendered to their loved one. To support this, a study by Downey et al. (2009) have identified pain and symptom control, family presence and support as critically important to a good death as defined by patients and families.

On the other hand, family members described their experiences and feelings when a loved one was receiving EOL care in the ICU. They reported that their dying loved one's serious condition and his or her dependence on the medical-technical equipment were experienced as

more frightening than the equipment as such. Being confronted with the threat of loss, they maintained a vigil while at the same time trusting the care provided to their loved one and trying to adapt/understand the whole situation. The family reported the need for privacy and togetherness so as to experience reconciliation. It was also reported that adequate communication, good decision making, and respect and compassion shown to both the dying patient and their family were key determinants to family satisfaction. This has been supported by Kirchoff, Palzkill and Kowalkowski et al. (2008); Agard and Harder (2007) who stated that preparing families towards EOL care provides satisfaction and prevents ambiguous and disturbing memories.

In addition, family members wanted to be informed of any changes, have an opportunity to discuss treatment and have questions answered by nurses and doctors, have the same group of nurses provide care for consistency, have one hospital staff member act as the family contact so as to avoid confusion, have time with the patient in preparation for death and eventually have flexible visitation policies which maximize access between family members, their dying loved one and health care professionals. These findings are supported elsewhere by Davidson, Powers and Hedayat et al. (2007).

3A.9.3 Discussion and decision making processes

The following studies dealt with discussion and decision making during EOL care: Ho et al. (2005), Benbenishty et al. (2006), Hov et al. (2007b), Gries et al. (2008), McMillen (2008), Latour et al. (2009) and Lind et al. (2011).

The European guidelines advocate that nurses play an active role in EOL decision making within the clinical team (Carlet, Thijs & Antonelli, et al., 2004). However, the findings on discussion and decision making during EOL care in this review revealed that nurses perceived physician as the rightful initiator of discussion as well as the final decision maker. Nevertheless, a European study showed that most nurses were involved to a large extent in EOL decisions, but not as initiating the discussion and once a decision was made there was a sense of agreement between the health care team. It was also reported that senior nurses are often actively involved in EOL decisions than junior nurses because senior nurses have more

experience and are naturally likely to be involved. Less involvement was associated with cultural differences in different countries. Of most importance, nurses reported their role in supporting the family and being a patient advocate during this tough moment. Above all, the results indicated that nurses should be more involved in family-physician communication/decisions and contribute to building a team for family support.

Despite well documented strategies to prepare families for EOL decisions (Curtis & White, 2008), the families' perceptions in this review reveal ineffective and unclear communication strategy. In most cases, it was shown that relatives want a more active role in EOL discussion and decision making in order to communicate the patient's wishes. However, many considered their role to be unclear, and few of them experienced shared decision making. In addition, EOL decisions were discussed with the family in some of the cases and in some, the families were more often told than asked about EOL decisions. Discussions did not occur with families in many cases because the patient was unresponsive to maximal therapy or because the physician believed that the family would not understand. Family-physician disagreements that arose were significantly associated with less family satisfaction with decision making and decreased feelings of support during the process.

Spirituality as indicated by Carey and Cosgrove (2006) may provide a platform for family members to express themselves, feel comforted, cope with death and guilt of letting their loved one "go". In addition, spiritual support, encouraging and respecting prayer and adherence to cultural traditions help many patients and families to cope with illness, death, and dying (Browning, 2009). This review reported that family members felt more support and were more satisfied with the decision making process when spirituality was addressed during family meetings.

To sum up, a study by Morgan (2008) concluded that literature appraisal of EOL care indicate a paradigm shift from critical to palliative care. In other words, shift from reductionist approach to more humanistic approaches in the acute care setting. When treatment is deemed futile, quality EOL involving the assessment, ongoing assessment and care after death becomes the new goal for critical care team. To practice EOL competently,

nurses require organizational and educational support at local and national levels. Relevance to intensive care, nurses have an extraordinary opportunity to make a difference to the dying patient and their family and their acceptance of death.

3A.10 SUMMARY

This chapter presented methods and procedures undertaken during systematic review including its findings.

The following chapter presents the methodology and findings of the experiences of family members on EOL care in critical care unit.

CHAPTER 3B
EXPERIENCES OF FAMILY MEMBERS ON END-OF-LIFE CARE

3B.1 INTRODUCTION

In the previous chapter, the research design and methods including the findings of the systematic review were provided. This chapter refers to step 2 of stage I of the study and it begins with a presentation of the research methods. Following which, the biographic information of the family members' participants, findings and discussion of the major themes that arose with regard to the family members' experiences of End-Of-Life (EOL) care in the intensive care unit are presented. A brief conclusion of the findings and a summary concludes this chapter. In this section, the family whose relative was receiving EOL care was referred to as 'family' whereas their relative who was receiving EOL care was referred to as 'patient'. **Figure 3B.1** presents the summary of the presentation of this chapter.

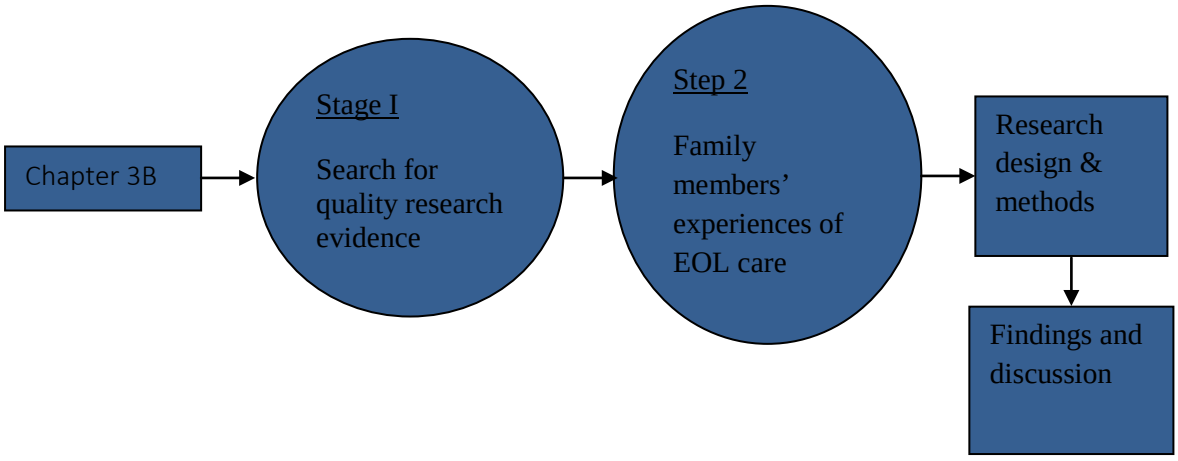


Figure 3B.1 A summary of the presentation of chapter 3B

3B.2 RESEARCH DESIGN

A descriptive, exploratory, qualitative design was used to describe the experiences of family members on EOL care.

3B.3 RESEARCH METHODS

Research methods are the techniques researchers use to structure a study and to gather and analyse information relevant to research question (Polit & Beck, 2012:12). These research methods which include target population, sample and sampling methods, data collection procedures, and strategies for analysing the data are discussed in the following section.

3B.3.1 Target population

Burns and Grove (2007) describe the target population as the entire set of individuals who meet the sampling criteria whereas an accessible population is the portion of the target population to which the researcher has reasonable access to. The target population for the family members included all the families who had a relative in the intensive care unit that was not for resuscitation or not for escalation of treatment between February, 2012 and April, 2012.

3B.3.2 Sampling and sample

Purposive sampling also referred to as judgmental sampling involves the conscious selection of certain subjects by the researcher (Burns & Grove, 2007:344). This type of sample is based entirely on the judgement of the researcher, in that a sample is composed of elements that contain the most characteristics, representative or typical attributes of the population that serve the purpose of the study best (de Vos, Strydom, Fouche, et al., 2011:392). ICU patient charts were used as a sampling frame. The families who met the inclusion criteria were approached for their consent to participate in the study. A non probability purposive sampling method was used to select family members of critically ill patients so as to elicit their experiences of EOL care. The families were selected until a point of saturation of themes was reached. Saturation point was attained after fifteen (n=15) participants were interviewed. In total, a sample of seventeen (n=17) family participants were interviewed.

Inclusion criteria for the family members of critical care patients included:

- Those whose adult relative had a ‘not for resuscitation’ or ‘not for escalation of treatment’ order on the ICU chart and were still in the ICU.
- Those who could communicate in English as the researcher is not sufficiently proficient in the many vernacular languages or in the many African regional languages (e.g. French and Portuguese) used by patients in these referral hospitals.
- Those who had undergone counselling about the change from curative to palliative or comfort management of their relative in the ICU.
- Those 18 years and older provided written consent to participate had been obtained.

3B.3.3 Data collection procedure

Successful execution of design and data gathering is determined by the accessibility of the setting and the researcher’s ability to build up and maintain relationships with gatekeepers and participants (de Vos, et al., 2011:325). Following permission from the relevant authorities to conduct research, the researcher purposively selected family members to be included in the study. The researcher had been working shifts in two of the participating ICUs as a nurse. Through this, the researcher was able to get to know the participants and the context and to allow for the establishment of a trust relationship between her and the participants.

At the time of data collection, the researcher identified patients who were not for resuscitation or not for escalation of treatment. When the researcher was not in the unit for some reason, she phoned the unit managers to find out if there was a patient who met the inclusion criteria as outlined in the section above. Once the patient was identified and the family had been counselled (the researcher also attended some counselling sessions and introduced herself thereafter to the family), the researcher personally approached the families and invited their participation after having explained the study in detail. Those families who accepted the invitation to participate selected one member of the family to participate in the one on one interview. An information letter outlining the purpose of the interview, one

consent form for inclusion in the study and the other one for tape recording (refer to **appendices J, K and L** respectively) were provided to the potential participants.

The researcher then met separately with each participant at a selected, quiet meeting room in the hospital during their own time while visiting the patient. The interview process started in an informal and friendly manner so that a relaxed and acceptable environment could be created (Kvale, 2009:55). The introductory phase involved explaining to the participants the purpose of the study, their expected role, clarifying the amount of time needed to complete the interview and the use of a tape recorder as recommended by Creswell (2007:134) and Kvale (2009). The interview setting was arranged in a manner that allowed the researcher and each participant to communicate on an equal level. There was no desk separating them. Participants' questions were answered to their satisfaction. At the beginning of each interview, participants were assured of anonymity and confidentiality and to ensure this, each participant was requested to provide a pseudonym of their choice to be used by the researcher. Two separate written consents were obtained, one for participation in the study and the other for the use of a tape recorder. The participants were assured that all the tapes will be kept in a locked cupboard whereas all the data will be kept safe under password protected computer.

Semi structured interviews used to gain a detailed picture of a participant's beliefs about, or perceptions of a particular topic were used as a means of data collection (Brink, Van Der Walt & Rensburg, 2008). This method of data collection gave the researcher and participant much more flexibility and the researcher was able to follow up particular interesting avenues that emerged in the interview while the participant was able to give a fuller picture (de Vos, et al., 2011:351). To ensure that all questions were covered, the researcher had a set of predetermined questions on an interview guide (refer to **appendix M**), but the interview was guided rather than dictated by the researcher's questions (Polit & Beck, 2012). Probes were also used to elicit additional information from the participants (Kvale, 2009).

To maintain the focus of the study, all of the participants were asked the same questions. Preceded by the following introductory comments, the participants were initially asked the question below during the interview session: “Thank you so much for offering to help me. I want to stress that I am grateful for your experience and expertise but the actual discussion on comfort or end of life care in the ICU does NOT apply to you personally”.

> *“Kindly describe how you would have liked your loved one to receive comfort care while admitted to ICU”?*

As varying perspectives of the family members’ experiences of comfort care at EOL became evident through analysis of the initial interviews, more focused and probing questions were asked and included in the interview schedule for clarity and to gain more elaborate descriptions of categories emerging from the data. The researcher had to ask the questions in a simple way as much as possible to enhance the participants’ understanding and response bearing in mind that English was not the participants’ first language. The question was therefore rephrased to be:

> *‘’Would you please tell me about your experiences towards the nursing care that you and your family member received while in the ICU”*

After the initial question, each participant was expected to proceed with the expression of her experience for some time without being interrupted by any probing questions. Some participants expressed their experiences and perceptions in summary form or at times they indicated that they had exhausted their views. In such cases, the researcher had to focus and direct the interview by use of probes and interviewing techniques. Interviewing techniques that were commonly used included: paraphrasing so as to enhance meaning, reflecting back to important things that have been said for expansion, clarification for unclear statements and minimal verbal/non verbal response with occasional nodding “mm, yes, yeah, OK” to allow the participant maximum opportunity to tell their story while at the same time to show that the researcher is listening (Kvale, 2009; de Vos, et al., 2011:345).

All the interviews were tape recorded to ensure that all the information was recorded for verbatim transcription (Kvale, 2009). To enrich the tape recorded interviews, field notes were written during or immediately after the interviews and inserted at relevant points during transcription. Field notes are written accounts of the things that the researcher hears, sees, experiences and thinks about in the course of the interviewing (de Vos, et al., 2011:359). After each interview, once the tape recorder was switched off, each of the participants was allowed to express their feelings about the interview. This was done as a means of debriefing because after a gasp of relief, some interviewees may then bring up topics that they did not feel safe raising with the tape recorder on (Kvale, 2009:56). Any new information that emerged was written down under field notes and later transferred to the relevant section during transcription. Each interview lasted between 30 to 45 minutes. Data analysis commenced immediately after the first interview and continued in parallel with ongoing data collection. In order to obtain greater richness of data in this study, seventeen participants were interviewed.

Data collection and data analysis continued concurrently until it was evident that no new information that added to the understanding of the categories and themes emerging from the interviews hence data collection was discontinued (Creswell, 2009). Data collection was extended for a period of two and half months; first because it was not common to find many patients who were not for resuscitation in the ICU within a short period. Secondly, some patients died too soon after the decision had been made to withdraw active treatment hence they had to be excluded in the study.

3B.3.4 Data analysis

Qualitative analysis is the non-numerical examination and interpretation of the findings for the purpose of discovering underlying meanings and patterns of relationships (de Vos, et al., 2011:399). Data collection and analysis took place simultaneously as interviews were transcribed verbatim immediately after the interview. The semi structured interviews with the family members were transcribed and analysed to establish the major themes that arose from the data about the family members' experiences of EOL care.

3B.3.4.1 Transcription of data

Each interview was transcribed verbatim in preparation for data analysis. Transcribing the interviews from an oral to a written mode structures the interview conversations in a form amenable to closer analysis and is in itself an initial analysis (Kvale, 2009:94). While transcribing interviews, the researcher has to ensure that the transcriptions are accurate, reflecting the totality of the interview experience and organized in a manner that facilitates analysis (Polit & Beck, 2012:557). In this study, the transcription was done word by word and empty spaces filled with field notes. Pauses were indicated by the word "pause". Recorded responses such as sighs or sharp reactions were written in brackets within the context of the statement. On completion of each transcript, the researcher checked for accuracy by simultaneously reading and listening to the audio-taped interview and making the necessary corrections.

3B.3.4.2 Steps of data analysis

During the data analysis process, the researcher was guided by the eight steps of analysing qualitative data as outlined by Tesch (1992). The following section briefly presents how each step was used in this study.

To begin with, the researcher read through all the transcripts carefully trying to get an overview of the interviews. Ideas were jotted down as they came to mind. In the second step, the researcher picked out an interview on the top of the pile, read through it and while reading kept asking herself what the interview was about. Any thoughts and ideas that came up to the researcher's mind were jotted down in the margin. After reading through a number of the transcripts, a list of all the topics identified was made in the third step. Similar topics were grouped together. The topics were then formed into columns. In step four, the topics obtained were abbreviated as codes, and each code was abbreviated next to the appropriate text in the transcript to check if new codes emerged.

In step five, the most descriptive wording for the obtained topics were formulated which were then converted into categories. Relationships between the categories were examined. Following this, a final decision on the abbreviation for each category was made. After which

all the data belonging to each of the categories were gathered in one place and thereafter an initial analysis was done. The transcribed interviews were also given to a co-coder to do independent analysis of data and to check that they corresponded with emerging themes. The co-coder did not make any alterations or additions to the themes that were already identified by the researcher. Finally, existing data were re-coded to reduce categories/themes from eight to five themes. For auditing purposes, refer to **appendix N** for an analysed transcript. Themes arising from this step were integrated with the other findings in steps 1, 3 and 4 and used as evidence for the development of best practice guidelines.

3B.3.5 Pilot study

A pilot study was conducted prior to the commencement of the main study. The purpose of a pilot study is to help the researcher fine-tune the study for the main inquiry and to determine whether the methodology, sampling, instruments and analysis are adequate and appropriate (Burns & Grove, 2007; de Vos, et al., 2011). The researcher conducted practice interview with two family members. This was undertaken to refine the technical aspects of tape recording, transcribing interviews and to improve the researcher's interviewing techniques. An evaluation of these skills was sought from three fellow students at the nursing department. No amendments were made on the interview guide as it was found to be practical hence the pilot interviews were included in the actual study.

3B.4 BIOGRAPHIC INFORMATION OF THE FAMILY PARTICIPANTS

Table 3B.1 presents the summary of the biographic information of the family participants. In total, 17 family members were formally interviewed in this study. Demographic information obtained from this sample indicated that the majority of the participants were female (58.82%; n=10). Black participants dominated in the study accounting for 76.47% (n=13) with white participants accounting for 23.53% (n=4) of the study participants. The ages of the participants ranged from 27 to 65 years. Days from which a decision was made varied among patients with the days ranging from day 4 to day 18 after ICU admission. The occurrence of patients' death after a decision was made ranged from 5 to 20 days (often between 1 to 4 days after decision had been made).

Table 3B.1 Biographic information of family members' participants

No.	Pseudonym	Gender	Race	Age (years)	Relationship with patient	Day of decision	Day of patient's death
1	Jane	Female	Black	27	Sister	10	11
2	Gloria	Female	White	65	Sister	18	20
3	Jack	Male	Black	40	Brother	9	12
4	John	Male	Black	32	Brother	5	7
5	Pinky	Female	Black	34	Daughter	10	13
6	Ben	Male	Black	37	Husband	5	6
7	Ryan	Male	White	36	Brother	14	16
8	Dave	Male	Black	43	Brother	9	12
9	Violet	Female	Black	50	Sister	5	7
10	Purity	Female	Black	36	Sister	4	6
11	Peter	Male	Black	39	Son	11	13
12	Maria	Female	Black	35	Niece	4	5
13	Rachael	Female	White	49	Wife	10	13
14	Sera	Female	White	27	Sister	9	11
15	Patience	Female	Black	41	Mother	6	7
16	Sipho	Male	Black	39	Son	17	19
17	Sma	Female	Black	37	Daughter	6	8

3B.5 FINDINGS AND DISCUSSION

The findings obtained from the interviews are presented in the following section. The findings are discussed in detail and illustrated by means of verbatim excerpts from interviews. This is followed by citation of relevant literature. Sub-themes identified have been used to further help to explain the major themes as will be explained under each relevant theme. Before the discussion of the findings, a summary of all the themes and sub-themes identified in this step of the study are presented in **table 3B.2**. In total, five themes and fifteen sub-themes were identified. For clarity, a summary of each theme and its sub-themes will be presented in a table format before commencing the description of the findings in the subsequent sections.

Table 3B.2 Themes and sub-themes emerging from family participants

MAJOR THEMES	SUB-THEMES
3B. 6 "MOST OF THE TIME WE ARE IN DARKNESS"	**3B.6.1** "Fetching information bit by bit" **3B.6.2** Progress report **3B.6.3.** Confusion about the information **3B.6.4** "Digging holes slowly in our hearts"
3B.7 EMOTIONAL SUPPORT	**3B.7.1** Hope for recovery **3B.7.2** Comfort measures **3B.7.3** Nurses' hospitality **3B.7.4** Empathy/compassion **3B.7.5** Nurses' presence
3B.8 INVOLVEMENT	**3B.8.1** Involvement in decision making process **3B.8.2** Involvement in direct patient care
3B.9 "YOU FEEL YOU SHOULD SEE HER FACE MORE OFTEN"	**3B.9.1** "You go home and you are just thinking" **3B.9.2** Being present till death
3B.10 SPIRITUAL SUPPORT	**3B.10.1** Prayers to the patient **3B.10.2** Religious leaders

3B.6 "MOST OF THE TIME WE ARE IN DARKNESS"

To begin with, **Table 3B.3** below indicates the first theme and its sub-themes that emerged from the family participants.

Table 3B.3 Theme one and its sub-themes

MAJOR THEME	SUB-THEMES
3B.6 "MOST OF THE TIME WE ARE IN DARKNESS"	**3B.6.1** "Fetching information bit by bit" **3B.6.2** Progress report **3B.6.3** Confusion about the information **3B.6.4** "Digging holes slowly in our hearts"

Before the discussion of each of the sub-themes, this major theme will now be discussed.

All of the participants in this study reported that communication and information sharing between them and the nurses is very important and should be done from the first day of patient's admission. Although a few study participants reported that communication was good with the nursing staff, the majority mentioned that they were not satisfied with the communication in the ICU and that they felt "they were in darkness". These participants mentioned that communication would enable them to understand exactly what was going on,

what was being done to their patients and what to expect. For example, out of those who said communication was good, three of them said:

> *"…when I phone they would give me the sister (nurse) that is with her to speak to….they told me exactly what is happening…they really spoke to me nicely and when we had questions, they explained anything we needed from them"* (Gloria).

> *"Sisters (nurses) tell you things when you ask and if they don't know they say you must see the doctor"* (Peter).

> *"…they have time for us to explain things they even give us time with him (patient) if we had any question, they referred us to the doctor. So, I can see they are trying their level best, they don't just give up and this process they are doing I think it is a very good process so that we as a family must accept, I know that we are still in denial but it comes with the stages"* (Maria).

Previous studies have documented adequate communication as one of the contributing factors towards the provision of end of life care and as an important determinant of satisfaction especially of families with EOL care in ICU (Cohen, Sprung, Sjokovist, et al., 2005; Kjerulf, Regehr, Popova, et al., 2005; Hancock, Clayton, Parker, et al., 2007; Gries, Curtis, Wall, et al., 2008; Efstathiou & Clifford, 2011). In contrast, the majority of the participants (79%) in a study by Kjerulf et al. (2005) were satisfied or very satisfied with the amount of information that they received.

While some participants had good experiences with regard to communication in the ICU, some of them encountered difficulties with the communication between them and the nurses. They expressed the need for the ICU staff to have time for them and to communicate to them clearly so that they were able to understand what was going on with their loved one. One of the study participants stated:

> *"…we need to understand what is happening in the process and they (nurses) must explain to us things so that we can also understand whatever is happening because*

surely, most of the time is like we are in the darkness because we don't know what is happening (sighs). *They must explain what is going on now, they must explain all those machines, what is happening with the heartbeat, yeah so that you can understand"* (Pinky).

Another participant expressed himself this way:

"I didn't really understand the situation as a whole ... I found myself not knowing the seriousness and I was quite confused and in that to me, you know, I was a little bit lost and the family as well" (Ryan).

Similarly, one of them reported:

"…only the sister (nurse) that was taking care of her yesterday, she explained that they were trying this other machine and they are trying other medication; but the others when we asked they wanted us to ask the doctor because they didn't want to divulge (pauses). With the doctors not being around and the sisters (nurses) not divulging the information, I can say we have not received quite enough information as to what is happening and we still have some question marks that I may want to ask" (Purity).

Some of the participants felt that nurses concentrate a lot with the care of the patients but they don't accommodate the families. One of them stated that:

"…they put more emphasis on the care of the patient and they try as much as possible to prevent the family to be involved with what is really happening to the patient. Like certain medical information that, you don't have access to your close relative's information as per the immediate effect of the accident or whatever happened. It makes me to…. err to doubt and it increases my stress level" (Ben).

It has been found that families of ICU patients express the need for unambiguous communication and clear information about their loved one's condition and prognosis as they

often have difficulties understanding and interpreting the information presented (Lind, Lorem and Nortvedt et al. (2011:1148). The findings in a study by Fridh, Forsberg and Bergbom (2009b:116) revealed a lack of 'piloting' which meant family not being invited into as well as excluded from a caring relationship and this led to feelings of loneliness and abandonment as well as providing scope for their own interpretations, thus increasing the risk of misunderstanding. Similarly, in a review of 51 studies examining communication of prognostic information with adult patients experiencing life-limiting illness, it was found that health care professionals consistently underestimate patients' or families' needs for information, while they simultaneously overestimate their understanding of prognosis and awareness of end-of-life issues (Hancock, et al., 2007).

Communication and informing the family about the situation is crucial to ensure that the futile condition is understood and can be accepted (Cohen, et al., 2005). ICU caregivers should fully disclose the patient's current status and prognosis to designated families and clearly explain all reasonable management options (Davidson, Powers & Hedayat, et al., 2007:608). On the other hand, standardizing generic information to be given to all families will enable even less experienced nurses to know what to say while tailoring this information to the clinical situation of each patient and practice of the clinician so as to help the preparation mirror the actual experience of the family members more closely (Kirchhoff, Palzkill, Kowalkowski, et al., 2008:120).

While the findings elsewhere found that the nurses were too busy for the families (Kjerulf, et al., 2005), other studies support that providing more time for family members to talk can improve communication and reduce the burden of sorrow for families (Efstathiou & Clifford, 2011). Similarly, another study revealed that nurses rarely participated in meetings between families and physicians and bedside communication focused on everyday issues and the wellbeing of the patient. Families perceived the nurses as friendly and compassionate, but vague and reluctant to give information (Lind, et al., 2011:1146).

A few families interviewed in this study reported that the nurses communicated and gave them information in a proficient way. These participants expressed that it felt better when

someone talked to them and told them what was going on with their patient. It therefore appears that nurses need to improve their communication skills that seem to be inadequate so as to satisfy family members.

On the other hand, the majority of the families interviewed in this study were not satisfied with the information received and the communication between them and the ICU staff. From the findings, it could be speculated that, when doctors give information as it is regarded as their duty in this setting, they either give it hastily or in a manner that the families do not understand. The other reason why families appear not to understand might be due to the fact that meetings for such discussions are often limited. It is also thought that families do not get enough information as doctors may not be able to see them on a regular basis based on the workload in the unit and given the fact that nurses refuse to take this as part of their 'role' and believe the information should only be given by the doctor. It is also apparent that families feel neglected by the nurses as they tend to concentrate more on patient care; forgetting that their nursing care at end of life encompasses both the patient's and the family's holistic care.

3B.6.1 "Fetching information bit by bit"

Receiving information about the patient brought a sense of relief to all families. Family participants wanted to receive information but, surprisingly, they reported that in most cases, they had to ask to be given information about the patient. The families were only asked to meet the doctor once so that they could receive information about the patient's prognosis which was only given when the doctors had decided that the treatment was futile and they had to move to palliative management. The doctor would then "break the news" to them about their loved one's change of condition or not responding to treatment as a means of counselling them to be prepared for any outcome, including death.

In the cases where the doctor did not ask to speak to the family, the family themselves had to ask to be given information on whatever questions they had, this was referred to as "fetching information bit by bit" . For example, some of the participants said:

"The problem is that the doctor or nurse will not come to you and tell you…err, this is what is happening with your wife unless you approach him and say to him, what is really happening? This is the only way I managed to get full information about my wife" (Ben).

"If we needed to ask something, then we go to them and ask" (*Pinky).*

Some mentioned that they have to ask if they have anything they want to know and once they have received the answers then they feel better. One of them said:

"…we asked the sisters (nurses) and the doctors and the more we got answers to what we wanted to know, the more relieved we got" (Gloria).

With the doctors being busy and the nurses not divulging information, other families concurred that they had to wait for the doctor in order to receive information. One explained:

"…we don't always get to see the doctor and sometimes you could be lucky to catch them….you see them walking out and you are like, sorry doctor can I please ask you something?" (Ryan).

Some participants mentioned that they always ask, they ask daily so that they know what is happening with the patient. Two of them said:

"…so we have to ask them (nurses), it is not like we know everything about the patient, I mean they mustn't just wait for me to ask hey, how is it? …and if you don't ask them, they don't care and if you don't ask anything you just see and go but we always ask. And now it is like you fetching information bit by bit from them… I had to come here and dig the information of what is going on, how far are you," (Maria).

And:

"….we ask them to tell us what is going on every day because it will make us feel better that at least I understand this and that about his sickness and treatment" (Jack).

It is acknowledged that provision of clear information in a variety of forms to the dying patient's family will help and should be enhanced by the availability of health care professionals for the discussions needed to improve the provision of effective end of life care (Efstathiou & Clifford, 2011:120). The findings in this study agree with those by Kirchhoff et al. (2008:120) whereby participants reported that they had to ask for information that was not provided to them. The participants expressed frustration over not having a better understanding of what was going on, a situation that led to anxiety and nervousness. These findings are also similar to the findings in a study by Lind et al. (2011:1145) who reported that few participants experienced regular physician communication. The physicians often seemed busy, did not keep appointments, and left the family waiting for hours. When family members did succeed in meeting a doctor, they found they were rarely given enough time for proper dialog.

When a patients' illness is sudden, there is often little opportunity for clinicians to establish a relationship with the family before it becomes necessary to communicate bad news and the sharing of information about diagnosis, prognosis, treatment options and complications may often occur in a single conversation (Longden, 2011:133). Despite of this, family meetings with the multi-professional team should begin within 24 to 48 hours after ICU admission and should be repeated as dictated by the condition of the patient so as to deliver effective and regular information (Davidson, et al., 2007:608).

Following consultation with one of the ICU doctors and as observed personally by the researcher, after the decision had been made, for the first time, the families could be contacted to come to the hospital and meet the doctor or they could be asked to meet the doctor when they come for visiting. It was found out that, after the first counselling session, the same participants did not have any other regular meetings with the doctors to discuss anything unless a new family member who had not received the information or themselves requested for explanations about the progress and the status of the patient from the doctor. The reasons as to why families had to ask all the time might be because they only got one chance to meet the doctor for information and this one chance meeting may not meet all the families' informational needs as questions and concerns regarding the care of the patient could arise daily.

3B.6.2 Progress report

The majority of the participating family members expressed the need for receiving information about the patient's progress on a daily basis. They mentioned that this would help them know what to expect from the beginning of admission, understand what is being done and why it is being done as this would make them feel better. For example some of them had this to say:

> *"I would have loved to receive information everyday about what is happening… I thought if I have somebody sick I should get the necessary information about the condition and how she is doing from the first day so that I know (silence) OK today it is this and that and today may be it is getting better or worse (mm) and this make you feel better and relaxed just to know about what is going on"* (Ben).

> *"…tell us what is going on every day we come to see him because it will make us feel better"* (Jack).

> *"I was asking myself why all the time they did not tell us and now it is late and they come to tell us"* (Pinky).

Some of them wished they could be contacted over the phone when they were not able to come and see the patient in the ICU. It was reported that no phone calls were made telling them how the patient was progressing but instead, those that had been contacted over the phone were being told by the nurses or doctors that the patient's condition had changed and they must come to the ICU. One of them said:

> *"….the hospital always calls you either because someone is changed condition or he is dead but I mean why not just inform us from day one that today he is this and that? It will help to calm us down because we know what to expect. This is an ICU and it could be helpful to us as family to receive continuous report about our patients; maybe at least twice a day or even once a day. Because if you are at home, you panic a lot because you don't know really what is going on and every time the phone rings it is even worse because now you think maybe he is gone"* (Maria).

In most cases, the families had to phone the unit to find out what was going on with the patient at that time. For example, one participant had this to say:

> *"When I phone they would give me the sister (nurse) that is with her to speak to….they told me exactly what is happening"* (Gloria).

Findings in this study agree with that of Kirchhoff et al. (2008:120) who found that participants wished they had been provided with a sequential order of events because this information would have helped them organize themselves better. The need for prompt notification of any changes in the patient's status and regular updates in an understandable language has also been reported by Davidson et al. (2007).

Different from the findings in this study, Coombs, Addingon-Hall and Long-Sutehall (2012:523) report that in their study, medical staff gave formal intermittent updates through planned family conferences, whilst nursing staff offered on-going bed-side care. This support focused on family understating of events to date, and family coping in the face of critical illness of their family member. Families need regular meetings with physicians with an appropriate balance between hope for survival and accurate and straightforward information about the illness and the prognosis (Lind, et al., 2011:1145).

In this study, family members interviewed felt that they did not receive a daily progress report of their loved one as they wished to have received. This might be due various reasons such as nurses' reluctance to disclose information, nurses' assumption that the family could ask in case they needed to know anything, lack of time to attend to the family as the nurse could be busy attending to the patient's daily needs or just the thought that it is the 'doctors' role' to give information about the patient.

3B.6.3 Confusion about the information

Nurses and doctors in the participating hospitals work in shifts. Families will always meet almost different staff on duty every day they come to visit the patient. The participants

mentioned that they had met different staff (both nurses and doctors) taking care of their loved one. Some of these participants reported that the explanations they were given in two different occasions by different staff were quite confusing. They reported that, even if the patient were to die, they will always remain confused about what really went on and they will never be in peace. One of the participants said:

> *"…you meet different people all the time you come …the family should also receive same information rather than different kinds of messages from different people because this can really confuse you"* (Ryan).

For Maria, her uncle was transferred in from another hospital with a diagnosis of organophosphate poisoning, on arrival to the ICU, she was told her uncle had no signs of poisoning from the blood results but they suspected hypertensive stroke or brain death due to hypoxia from the endotracheal tube that was not properly inserted. To her, it was so confusing and she didn't understand about the diagnosis. She said:

> "*…with all these different information,* it is difficult *we are not really sure and even if he goes (dies) we will never be in peace because we are not sure exactly what happened ....it is confusing, ha ha it is confusing (shakes her head) it is confusing. I think before they can go to the family, hey, they must communicate and report one thing, another one mustn't say this. And they promised to call, those people who promised to call me, they are working night duty so these ones on day they are not aware I was supposed to be called so it means between them, they are not communicating"* (Maria).

Consistency in nursing care may be difficult in an ICU with daily nursing rotation and changing assignments based on acuity and staffing (Kjerulf, et al., 2005). Due to this, the family may hear various and divergent information and opinions, both formal and informal, regarding the patient's condition, creating further confusion (Beckstrand & Kirchhoff, 2005). For example, in a study by Longden (2011:133), feelings of mistrust and unease were identified when a number of health professionals were involved in information giving as this was found to lead to conflicting information and negative feelings. Other families elsewhere

have reported being left with ambiguous information (Kirchhoff, et al., 2008:120). Another study revealed that inconsistent information given to family members about the patient's condition was associated with significantly high risk of symptoms of depression in the recipients (McAdam & Puntillo, 2009:203).

As mentioned by participants in this study, the lack of communication and collegiality between the therapeutic multi-disciplinary team emerged as one of the most problematic findings. In a study by Langley and Schmollgruber (2011:73), a lack of communication prevents adequate information being shared with the family, the patient and the members of the team.

Family participants interviewed in this study reported that the information they received from different staff members was confusing. It is true that continuity of care is not possible because in each shift, you will find a different person caring for the patient. It appears that there might be a problem with handing over of the patients' report as well as documentation. This could also be attributed to a lack of collaboration between the ICU team. Hence what doctors know may not be known by the nurses and vice versa. Consequently, a breakdown of information ensues all the way from the staff to the families, leading to confusion not only among families but also among the ICU team.

3B.6.4 "Digging holes slowly in our hearts"

In all the cases, participants were given information about the patient's poor prognosis and the need for transition to palliative management including expectations in this process. Some of the study participants reported that they had been told and everything explained to them but they kept worrying because they did not know what they should do from the time the information was told to them until the time the patient dies or after death. They expressed that it was hard just to sit and wait for death to occur not knowing what to do. This brought about worries and fears of the unknown to these families as they kept asking themselves "what to do" at such a time and this has been referred to by one participant as "digging holes slowly in our hearts". To some, waiting as explained by one of the participants is:

> *"…it is a trauma, it is a trauma. We don't know if he is going to good or bad (pauses) you see it is very hard to us seeing him lying like this suffering. It is painful, seeing him go, it will be painful but the pain will ease. Every time when you come here he is like this, now he is digging holes slowly and slowly in our hearts because the more he stays that way without improving, the more he suffers and the more we get stressed and not knowing what to expect and when"* (Maria).

Another participant said:

> *"…the waiting is just hard because you don't know what is going to happen but we just have to wait. The waiting is just difficult and other people don't realize that. We just wish they can just keep her comfortable and pain free…we know she is going to pass away. I am not sure what to do or ask when she has gone. I don't know what is going to happen after she is gone, what do we do?"* (Gloria).

Not knowing what to do was a source of worry. Some of the participants said:

> *"I am really worried and I don't know what is going to happen anytime or what to do… it is not easy to us family because we don't know what to do"* (Jack).

> *"…we should be told what to expect whenever we come in so that we are not worrying too much"* (Ryan).

> *"…what happens if someone is no more and you are not around, let's say it is at night? Because if they say he may not be well again then errr you know (pauses) and how do we know about things?"* (Violet).

Similar to the findings in this study, participants in a study by Kirchhoff et al. (2008:118) that dealt with preparation of families of ICU patients for withdrawal of treatment expressed worries as they did not know what to expect or what to do. Their study found out that families asked so many questions: specifically how long it would take, whether the patient would be in pain, what would be done, what they would see, how they could interact with their loved one, if symptoms would be distressing and what would be provided by staff.

Contrary to the findings in this study, Coombs et al. (2012:524) in their study found out that transitioning to end of life care could take hours/days/weeks. In each case, once the decision had been made, families were often prepared as to what to expect. Such discussions were usually staggered and staged with the aim of enabling families to understand a lack of progress or lack of recovery, the lack of treatment options remaining and the outcome for the patient. This kind of support has also been reported by Bell (2007).

In this study, while each patient's condition differed, no one knew exactly when death would occur. Death occurred within one to four days after the decision had been made. It is clear that the families were left to wonder how events would evolve after the discussion about the possibility of the patient dying. This is due to the fact that the families did not have frequent meetings with staff to discuss about what to expect and for them to ask questions if they had any. This would have been the only way which would have prepared them of what to expect and what to do, thus reducing their worries and heartache. The families might have also been scared to approach staff and ask questions concerning what to expect and what to do as expressed by one participant who said she thought it was the nurses' time to relax when it is visiting time.

3B.7 EMOTIONAL SUPPORT

The table below (**Table 3B.4**) presents a summary of the second theme that emerged from this step of the study and its related sub-themes.

Table 3B.4 Theme two and its related sub-themes

MAJOR THEME	SUB-THEMES
3B.7 EMOTIONAL SUPPORT	**3B.7.1** Hope for recovery **3B.7.2** Comfort measures **3B.7.3** Nurses' hospitality **3B.7.4** Empathy/compassion **3B.7.5** Nurses' presence

The section below discusses this major theme followed by the presentation of each of its associated sub-themes.

As discussed in this section, another major theme that emerged from participants' comments was concerned with emotional support after the decision had been made regarding transition to palliative management. All participants expressed feelings of anxiety, pain, hardships, feeling bad, frustrations, stress, confusion, worry, fear and disturbance. They had not been prepared to hear such distressing information about the patients as they expected that they would get better. Some participants said:

> *"…you feel like you don't know actually what to do, you are scared first of all, you are worried"* (Jane).

> *"…it is very painful to hear that because we were thinking he was going to come up and recover… you get confused and it is really painful, it is so much stress"* (Jack).

> *"…we really feel bad as the family because we actually thought that our brother is going to rise I am so frustrated, I am really confused I don't know what to do, we don't know what to say"* (John).

> *"we thought he was going to be better because he was off the ventilator and the tube was removed and then he went down again, I mean he got sick again and we are so worried"* (Ryan).

As most critically ill patients are not able to communicate, emotional support has been mainly focused on the patients' family (Efstathiou & Clifford, 2011:118). As found in their study (Fridh, et al., 2009b:113) the admission of a loved one to the ICU and being informed that he or she was not expected to survive was experienced as a shock and family members were not prepared for the fact that his or her life would end so soon.

A study by Kirchhoff et al. (2008:120) revealed that family participants reported that nurses felt like part of the family to them and, as bad as everything was, nurses made it easy as it could have been. Similar to the findings in this study, the majority of the family members (1

in 3) in a study by Teno, Gruneir, Schwartz et al. (2007) stated that there was inadequate emotional support for the family. High levels of anxiety and depression among family members of critically ill patients because of the absence of regular discussions between health care professionals and family have previously been reported (Efstathiou & Clifford, 2011:119).

In this study, it is evident that families were finding it hard to cope emotionally. This could be attributed to the fact that they were not involved in a series of discussions as a form of support and preparation for the patient's outcome throughout the time of admission to the ICU. Their expression of emotional suffering indicates that they did not have adequate support at the time they needed it most and that the nurses should have supported them in order to lighten their difficulties as they faced the imminent death of their family member.

When asked what they would wish to be done to them at such a time, participants expressed their needs which will be discussed in the following section under four sub-themes arising from this major theme.

3B.7.1 Hope for recovery

Hope was one of the aspects valued by all participants during this time in their lives. They had hope of recovery of their family member. They all said that they understood what had been explained to them by the doctor about the prognosis being poor but it was still hard for them to accept this and let it go. They used hope to cope and to console themselves that their family member was probably not going to die even if the doctors said he or she might die. For example, some participants believed that even if the doctors say the patient may not survive, they had hope that God is the only person who knows every ones' life and he may bring back their loved ones to the state in which they were at first. They explained:

> *"…we can only hope for the best, the doctor say she has to fight so all we need is to have faith because we are not God to control things"* (Purity).

> *"…we have put everything in God and we have hopes even if the doctors say no chances because God is the only person who knows everything as a creator"* (John).

Families of ICU patients have a variety of needs and the highest on the list is the need to maintain hope of which if not met can lead to rise in stress levels (Davidson et al., 2007:608). The definition of hope as defined by these authors may extend past the absence of death and include hope for a pain-free and a dignified death or hope for more time or quality time together.

Comparable to these findings, the findings in a study by Wiegand (2008:1117) revealed that family members were told the seriousness of their family member's illness or injuries, yet although family members heard the news they did not necessarily believe it. They needed time to understand the prognosis and it took them time to understand that the patient was never going to be the same person again. They hoped that their family member would beat the odds and respond to treatment, they waited and hoped that the patient would open his/her eyes, squeeze a hand or wiggle a toe.

Some believed in miracles. Two of the study participants who had hope that miracles might happen said:

> *"…if God raised a lot of people from dead then he is able to still do miracles even at present and bring him back to us"* (Rachael).

And

> *"…somehow, I still believe that wonders may happen and he may get well again because we talk to ancestors to always protect him and I hope they will hear us"* (Violet).

Related to the findings in this study, the families in a study by Wiegand (2008:1119) stated that, immediately after the patient's illness, they were very hopeful for healing and recovery.

All of them were very hopeful that the outcome would be good. When the condition of each patient failed to improve or in some cases deteriorated, families often hoped for a miracle and this hope continued up until the very end. In another study, nurses and doctors repeated information to the family members and gave an honest description of the seriousness of the situation, which helped the close relatives to realise that there was no hope (Fridh, et al., 2009b:113).

In this study, family members who were interviewed had hope that their patient was going to be well despite of the prognosis being poor. They all understood what the doctors told them about the patient's condition but still they were not prepared for the worst. This hope may be attributed to the fact that the families depended upon and trusted that ICU, being a place where patients are highly cared for with the presence of staff and all the machines and equipment as compared to other wards, would have cured the patient. It was hard for the families to believe the news and they hoped that a miracle would happen despite the prognosis being poor. Families being full of hope that the patient would recover might indicate that the ICU team did not frequently inform them about the seriousness of the condition. This might have helped them to accept the nearing death of the patient and alleviated their anxiety.

3B.7.2 Comfort measures

All family participants wanted to be reassured that the patient would be kept pain free, clean and as comfortable as possible even up to the end. For example two of them said:

> *"I met one of them (nurses) at the bed side the day they told us our daughter was possibly not going to live and she spoke to us, she reassured us and I was really touched…but I just told her to make her as comfortable as possible even if we are going to lose her"* (Gloria).

> *"…what I want to ask the nurses is to do everything possible to him in relation to reducing the pain my dad might feel in the process I would really like them not to leave him suffering"* (Peter).

According to Puntillo, Morris, Thompson et al. (2004), pain is one of the most prevalent symptoms in critical care as it is usually associated with procedures such as suctioning, turning, and the presence of endotracheal tubes which are the procedures that patients dying in critical care are subjected to as nurses aim to keep them comfortable. For the relief of pain, discomfort, anxiety and distress, opioids and sedatives are commonly used (Efstathiou & Clifford, 2011:119).

The majority felt that the patient was comfortable in the ICU. This was based on the physical appearance of the patient at the time when the family was around. They had these to say:

> *"…each and every time we came to visit he was looking comfortable in bed and clean all the time"* (John).
>
> *"…all the time you can see her clean and lying in bed quietly and she is looking like somebody that was well cared for"* (Pinky).
>
> *"…they keep her clean and they make sure she is safe"* (Dave).
>
> *"you see them (nurses) busy with them and they keep them (patients) clean and you see them (nurses) always busy because most of the time we are here either me or my younger sister and we see that they are doing their best to the patient"* (Violet).
>
> *"…there are some sisters who really go out of their way (mm) to… to do the job while others don't do the job. Every time we come to visit he is clean and comfortable and I must say some do their job"* (Ryan).

Similar to the findings in this study, Kjerulf et al. (2005) report that majority (68%) of the family respondents in their study believed that their family member was comfortable. Personal hygiene and physical care during end of life are considered important to each and every patient as this ensures that the patient's dignity is maintained at all times and the patient is as comfortable as possible (http://www.ana-nursing.co.uk/end-of-life.aspx). This also creates a peaceful and relaxed atmosphere for the friends and family who will wish to visit

during this challenging time. Stapleton, Engelberg, Wenrich et al. (2006) report that family members' experiences may be improved by supporting their decisions regarding end of life care and by assuring them that excellent care will continue to be provided with special attention to the comfort of the patient.

Apart from patients' physical appearance, the family also used other things like noise in the patients' surrounding to judge the comfort level. One participant said:

> *"They were very noisy especially this early morning at 5 a.m. when they called in and they said he is not so well would you please come. So when I came in, the place was so noisy, laughing, laughing, and this is an ICU. I myself, I was so uncomfortable about it, and what do you think the patients feel?"* (Ryan).

ICU is indeed a noisy environment for patients and its intensity within the ICU far exceeds that found in ward-based environments and in many cases is consistent throughout a 24-h period with its levels ranging from 59 to 83 dB (A) being higher than the recommended levels (Christensen, 2007:197). Other than sleep disturbance noise produces detrimental effects such as stress and stimulation of the cardiovascular and endocrine systems to ICU patients (Pugh, Jones & Griffiths, 2007).

In this study, all family members that were interviewed expressed the need for their patient to be kept as comfortable as possible. Most of them were satisfied with the way the patient was kept clean and comfortable. This shows that despite of the discussion regarding futility of care; nurses still care for patients and still treat them the same way as other patients whose full recovery is expected by keeping them clean and free of pain. These patients were not neglected but their dignity was always upheld by the nurses. However, one aspect that raised concerns about lack of comfort was that ICU was noisy. The source of noise as reported in the findings was from the nurses. This could have been from daily communication among the staff in the unit which apparently was done in loud voices to an extent that it became irritating to families.

3B.7.3 Nurses' hospitality

While some participants reported that they were treated well by the nurses, some felt that the nurses did not receive them to ICU in a good way. They expressed that it was hard to cope with a loved one so sick and in their final days yet some nurses never seemed to care much about their presence and the stress they were undergoing. Some family participants had positive experiences towards nurses' hospitality and one of them said:

> "…you get courtesy on arrival, they give you attention, hospitality has been very excellent, the nurses are friendly and they have time for us to explain things yeah they don't just leave you like that*"…they are talking to me, they are reassuring me and I feel relaxed even if it is difficult but it makes a lot of difference"* (Maria).

Another one said:

> *"…I have seen good nurses who are jovial and smiling and they greet you and even give you a hug some are so cold (folds her hands and sits back) and they don't tell you some things or talk to you freely (mm) and sometimes you feel unwanted or something but if someone can talk and encourage and do something you know, it gets better"* (Rachael).

Surprisingly, the majority felt that the hospitality they received from the nurses was not good. Two of them said:

> *"They (nurses) don't come and say to you how are you today, how did you sleep? How are you coping?"* (Pinky).

> *"…it would be really nice if I come in and someone attends to me like I am a human being and this will really make a huge huge difference by lifting my spirit and make me feel that they care and they feel for us"* (Ryan).

Another participant felt that the nurses were not so supportive to him but rather they gave much of their attention to the patients. He said:

"…no one really has given me any form of support (mm), no one told me anything but I didn't realize it is part of what they should be doing because they are here for the patient and not me. So I just tried to console myself through it all because it was something under control and I felt I could manage…they focus more on the care of the patient rather than giving support to the families who are affected. They don't speak to you and when they do, they just do it in very few minutes" (Ben).

In contrast to the findings in this study, Fridh et al. (2009b) found that most relatives perceived ICU as welcoming; they and their ill loved one were treated with respect, were met at the door and accompanied into the patient's room. Yoo, Lee and Chang (2008:231) stated that nurses should respect and support the patient's family members as caregivers. Nurses should always remember that this is a basic duty which eventually has a positive influence on both the EOL patient and the patient's family.

From the findings in this study, it would appear that majority of the participants interviewed were not happy about the hospitality they received while a few were happy. This may be attributed to the attitudes that each nurse carries in themselves. One should bear in mind that peoples' personalities differ and the character in one person may not be in another person that is why there is a mixture of families' experiences towards receptions in the ICU. In addition, absence of the nurses in the patient's room as discussed in section 3B.7.5 could contribute to a perception of poor hospitality as families will feel unwelcome when the nurses are seated at the nursing station while the families are alone in the patient's room. Their coming in to the room to attend to the patient and leaving as reported may give an impression of not caring about the family.

3B.7.4 Empathy/compassion

All participants expressed the need of empathy and compassion during this time. While some were satisfied with the way they received this care, others were totally unsatisfied about it based on the reception they had while in the ICU. Some of them experienced compassionate concern expressed in different ways, for example two of them said:

"…the care has been good, very very good, they were so nice and they greet you even if they don't know you. The first time we arrived here they were so nice and they greeted us and the one that was with my dad was very patient with us when we asked things she could tell us in a good manner" (Peter).

"…some could not realize I was stressed but some were very good to me, she did hug me to say sorry so I can say she was very supportive towards us as a family" (Rachael).

Other participants wanted some recognition of their circumstances to be indicated by the nurses. They felt that nurses did not display empathy and they needed them to 'step in their shoes' and get a sense of what it means to be in such a state. They had this to say:

"They (nurses) must have empathy (pauses) they must put themselves in someone's shoe and relate how they are feeling and see the pain that someone is going through" (Jane).

"…they (nurses) won't know if they are not in such a situation as we are; only the person in such a situation understands what it means." (Purity).

Another one said:

"I just want to say nurses must be a little bit more compassionate, compassionate in the sense that they must speak to the patients and to the families nicely…I mean little things matter, you need to have courtesy and in such situations you must put yourself in somebody else's shoe and say, wait a minute, if this is me what or how do I want to be treated. I think too many complaints from us have somehow affected our relationship with the nurses. I am very sure the attitude they have towards us might be transferred to my brother and you never know how they treat him when we are away from him" (Ryan).

For effective and compassionate provision of end of life care, nurses need to promote patient and family-centred decision making through effective communication with all involved in the patient's care (Efstathiou & Clifford, 2011:120). Otto (2010:74) mentions that providing excellent care to dying patients and their families require expertise as well as compassion. Displaying empathy conveys humanity and matters to families (Longden, 2011:134).

In this study, some family members felt that nurses were compassionate whereas some felt that they were not. It could be that in most cases, nurses who were not compassionate to the families did not put themselves in the families' situation or did not feel what the family was going through. While some offered support, seemingly others went on with their daily duties not appearing to acknowledge the strain the family was going through. In addition, it could be hard for someone to realize what it means to have a loved one dying if never having been affected personally as expressed by one participant (Purity).

3B.7.5 Nurses' presence

The participants reported that they needed someone to talk to and express their feelings but they did not have anyone to talk to. They could not find any nurse in the patients' room when they came to visit and they were afraid to go and disturb them. For example one participant explained:

> *"…sometimes you come and you don't talk to anyone because they (nurses) don't come. They were sitting at the reception and I was thinking, may be if it is time for visitors it is their time to relax or what? I don't know, and if we needed to ask something then we go to them and ask. Sometimes we could go in and we are wondering why she has this and that attached to her, you know, and how she is feeling, how she is you know so many questions we could ask ourselves when we were in her room. I am thinking if the nurse was always there with us then we were going to ask and may be go home at least relieved to know the answers to some of our questions"* (Pinky).

A few of them found a nurse in the patients' room. They observed what nurses did when they came to the patient's room and they reported that a nurse would only come in to check on the patient, write on the ICU chart and go and that they never stayed longer. Two of them stated:

> *"…the nurse comes in to the room you know, and you know it is pain, it is pain medication or it is either time to draw bloods or do the writing, just that"* (Ryan).

> *"…sometimes when I got there I found two nurses in the room so I talked to them yeah, otherwise you have to go and look for them sometimes"* (Maria).

This behaviour of nurses not being present in the room to talk to the family made some of the families think that it was not the role of the nurses to speak to them about the patient. For example some said:

> *"…well, I didn't even know it was their responsibility to talk to us about things going on, but now I realize that it is also their duty not only for doctors. Besides hallo sister… not a lot, then of course us going to tell them to do a, b, c and d for my brother as I said earlier, there was really not so much to say* because we already felt unwanted by the way they treated us" (Ryan).

And

> *"…we didn't have much to talk with them (nurses)"* (Pinky).

One of the most fundamental roles nurses play in providing emotional support to families of critically ill patients is being at the bedside, providing comfort, a caring touch and a listening ear (Bach, Ploeg & Black, 2009). A pilot study conducted by Kirchhoff et al. (2008:118) revealed that several families asked the nurse researcher to be at bedside for support even though the nurse would not be involved in patient care. They mentioned their preferences for having a supportive person present. In addition, Beckstrand, Callister & Kirchhoff (2006)

suggested strategies to facilitate a good death and one of the strategies suggested was the presence of a nurse with the patient and families so that the patient does not die alone.

In this study, the findings showed that nurses rarely stay in the patient's room with the families when they are around. Instead, the nurses give families space to be alone with their loved one. While nurses think they are giving the family privacy, it is evident that they are causing stress to the family as families report that they wish someone was in the room with them to offer emotional support and a listening ear. The nurses' absence could be interpreted as affecting the relationship between them and the families and it is apparent that mistrust has emerged to the extent that, when some families have something to ask about the patient, they look for the doctor and not the nurse as they think this is not the nurses' duty.

3B.8 INVOLVEMENT

In **table 3B.5**, a summary of the third theme and its emerging sub-themes has been presented.

Table 3B.5 Summary of theme three including its sub-themes

MAJOR THEME	SUB-THEMES
3B.8 INVOLVEMENT	**3B.8.1** Involvement in decision making process **3B.8.2** Involvement in direct patient care

The following section will describe and discuss this theme followed by its sub-themes.

The third major theme that emerged is involvement. This included family involvement in the decision making process and the involvement in the direct care of the patient. These sub themes will be discussed in detail below.

3B.8.1 Involvement in decision making process

When asked whether they were involved in the decision making process, all participants reported that they were told about the decisions that were made towards the care of their loved ones but not involved in the discussion. They expressed the need to be involved in the decision making process. Statements illustrating this were:

"…they told us all the time that they are going do this and that" (Jack).

"No, nothing they never discussed with us" (Pinky).

"…they told me about anything they wanted to do" (Ben).

"…most of the time the doctors would tell us" (Ryan).

"…what they did was tell us and then they went ahead. But I mean telling me is not my consent, does the doctor have to do all these things without the consent of the family? But she did consult us but it was a verbal, we have never signed that 'doctor you can do it' it was just verbal, so we didn't know if he was done. I mean where is the evidence, if we can say no, we didn't agree" (Maria).

Decision making in the ICU is based on a partnership between the patient, his or her family, and the multi professional team (Davidson, et al., 2007:608). While they expected their contribution to the process to be important for the patient, families in a study by Lind et al. (2011:1148) reported that most families were merely told the decision; they were left with unanswered questions and sometimes doubted the decision. A study by Cohen et al (2005:1218) revealed similar findings whereby discussions did not occur with families in many cases. Similarly, Cohen et al. (2005) revealed that the family was more often told (88%) than asked (38%) about end of life decisions.

Involvement in decision making process was regarded as important because families felt that they know their relatives better than the doctors and nurses and are therefore, they are in a position to decide on what is best on behalf of their loved ones who are in a vulnerable state. The other reason why families needed to be involved in decision making process was that it enables them to know the plans of care from the beginning of treatment up to the end as this enhances satisfaction towards the care of their loved one. One of them said:

> *"…if he cannot talk for himself then he cannot say what he likes and what he does not like and so then family can come in and step in his shoe. I somehow think if it is possible, they must let us know and so that we can plan together as families. You know why? Because may be they want to know some things about him and I might know some of the things or questions they have about my husband even better than them"* (Rachael).

Critically ill patients are commonly unable to think and participate in decisions as they may be unconscious, intubated, sedated and ventilated (Bell, 2007). Therefore, much of the discussion about what is happening to the patient and decisions about treatment take place between the patient's family and the critical care physicians and nurses (Efstathiou & Clifford, 2011). Lind et al. (2011) indicated that relatives wanted a more active role in end of life decision making in order to communicate their patient's wishes. However, it has been reported that when physicians address their decision, there is no time for family participation (Lind, et al., 2011). In contrast to the findings in this study, family members in a study by Coombs et al. (2012:523) were involved in discussions, although this usually occurred once consensus from the health care team had been reached.

Based on the nature of their relatives' status during this study, all family members were in a position to be involved in discussions and decisions regarding the care of their family member. Although this should have taken place as has been supported in the literature, none was involved in the discussion and decision making process. They were all told about decisions that were made even though most of them wanted to be involved. The findings also can mean that once the physicians have decided, that is it for the family as expressed by the participant who thought she needed to agree and sign a consent that the nurses and doctors can go ahead with withdrawal of the patient's treatment but that was not available and still they went ahead. The families' autonomy and advocacy for the patient was not respected in that it was about being informed about the decision that had been made rather than shared decision making.

3B.8.2 Involvement in direct patient care

The majority of the participants mentioned that they would be happy to be involved in the care of their loved one at this time because this strengthens the bond between the patient and the family. They felt that their involvement will bring about peace of mind to them even after the death of their loved one because they will know they took part in offering the best care during the patients' last moments. Involvement in the care also meant that the patient would feel loved and cared for by the family even though all patients were not in a position to either see or talk to their families during the time before their death. Families believed that the patients could still hear and feel their presence even if they were not able to see and inside them, it was believed by the families to be joy and happiness just to have a sense of belonging. Two of them said:

> *"I can do the care because it is another method of saying goodbye in a nice way, of not dying alone. At least the family is there doing this, doing that. To my side as a family I must be satisfied that I did something for him. The patient needs us as family as much as we need him and he becomes more comfortable when he is with us as family"* (Maria).

This same participant also strongly believes in being actively involved in the care of a loved one. She talked from experience. Her mother was sick some years back and she played a very active role in her direct care and this, as she says has kept her in peace to date. She said:

> *"I could always come and stay with her. I even took leave just to be there for her and could hold her hand, wipe her face, help the sister to turn her until her last day. Even when she died I felt at peace and satisfied because I was with her all the way and up to now my heart is calm that she went in good hands and she was as comfortable as possible till the end"* (Maria).

And:

> *"…you get to be close and even if she dies, we will be at ease as family that we also did something to her and she was not totally left in the hands of; I will call it 'strangers'"* (Purity).

Families who care for a dying loved one both assist the family member to prepare for the end of life and prepare themselves for this impending loss (Kwak, Salmon, Acquaviva, et al., 2007). Davidson et al. (2007:609) reports that families are encouraged to provide as much care as the patient's condition will allow and they are comfortable providing.

Most families who were willing to take part in patient's direct care expressed their fear of doing such activities with their loved one surrounded by machines and attached to so many lines and tubes without the presence of a nurse. They mentioned that they would be happy to take part in the care but they needed a nurse to be around to supervise or direct them on what they should do to avoid any problems arising. One of them said:

> *"…you can be afraid to touch because you may spoil things but if we can do it with a nurse to help us then it is good"* (Peter).

Another one said:

> *"…you will come and she has all these things attached to her, the machines, and you are scared to touch because you think mm what if I mess, what if I switch the machine off accidentally? But if I can do whatever under supervision, then it would be great"* (Purity).

Similarly, one of them said:

> *"…they must get us involved there so that we can be close and feel connected while our loved one is still around us but they must teach us what to touch and what not to touch"* (Pinky).

In contrast, a few of the participants completely did not want to take part in the direct care of the patient as she was afraid she might do something wrong and preferred the nurse to do it instead. One of them said,

> *"I don't think I would love to participate in the basic care because I don't know what I will be doing because I am scared I might do the wrong thin., I would rather have the ICU staff do it because then they know how to handle her including the lines and tubes attached to her"* (Gloria).

While touch is typically considered a natural or untaught act, in the context of serious illness and the high tech environment of the ICU, nurses played a significant role in advising family members, coaching, and modelling "appropriate" touch (Happ, Swigart, Tate, et al., 2007). The findings in this study are similar to those found by Kirchhoff et al. (2008:120) whereby the participants expressed feelings of guilt over having touched the patient, being unsure if it was okay to do so. Yoo et al. (2008:223) indicate that families play an increasingly important role in care acting as care givers or decision makers rather than just being passive observers but families most often need guidance about their role during the care. It is also reported elsewhere that caregivers of family members near life's end report many benefits of care giving, such as an increased sense of meaning and self-worth, closer family ties, and increased self-efficacy in care giving tasks but need knowledge and skills related to patient care (Kwak, et al., 2007).

The majority of the participants interviewed in this study expressed the interest in participating in direct patient care as this meant a lot to them. This means if allowed to do so in these settings and if they are told what to do and how to do, it would be beneficial to such like families as this prepares them for the impending loss since their presence doing things for their loved one may make them satisfied that their loved one is comfortable by all means and that he is receiving a dignified care.

3B.9 "YOU FEEL YOU SHOULD SEE HER FACE MORE OFTEN"

In **table 3B.6**, the fourth theme and the sub-themes that emerged from family participants is presented in summary.

Table 3B.6 Theme four and its related sub-themes

MAJOR THEME	SUB-THEMES
3B.9 "YOU FEEL YOU SHOULD SEE HER FACE MORE OFTEN"	**3B.9.1** "You go home and you are just thinking" **3B.9.2** Being present till death

This fourth theme will now be discussed followed by each sub-theme that arose from it.

Under this theme, all participants mentioned that it felt better when they were around in the ICU just to see their loved one as this lessened their worries and stress level. Seeing made it easy to cope while being away increased their stress level and thinking. One participant said,

> *"You feel you should see her face more often than when you sit at home because you will keep worrying"* (Gloria).

Three sub themes arising from this major theme will be discussed below.

3B.9.1 "You go home and you are just thinking"

Participating ICUs had restricted visiting hours. Normally in these ICUs, families who have patients at end of life are given an open access to their patients in the ICU. Apparently not all the families were aware of these benefits as no one told them. Some of them expressed that it was hard for them to deal with the situation because they kept thinking a lot about their loved ones while they are at home. It almost became impossible for some participants to cope from one visiting time to the next visiting time. One of them said:

> *"…it is not easy, I feel bad, (sighs). It is not so easy because you don't know what is going to happen next. You go home and you are just thinking, you don't even sleep,*

and then you have to wait from now up to the following day to come and visit again and it is not easy because you think and think and think" (Jack).

Another one said:

"it is very disturbing if you bring his picture to mind and you see him lying there in hospital bed and then you are not seeing him" (John).

The need to have access to the patient any time was expressed by another participant this way:

"It is part of rehabilitation. It is part of rehab because if you chase me away, I will not be OK it means they don't have time for me. Instead of reassuring me they just say (sneers). It means they don't care, they don't care about my part they are only caring about their job and their patients. They don't include the families because now you know, this is time for the family spiritually, psychologically, everything" (Maria).

Some of them expressed that they could not be able to concentrate or move on because their minds were just focused on the lose that they were about to receive. Some participants explained:

"…it has been hard and you cannot go forward because you get confused and you think about bad things all the time" (Peter).

"…we can almost not move on just to know she is critically ill and her live may never change" (purity).

"…when I don't see him? oooooh, I can't sleep, I can't concentrate, I have had trouble at work, and my boss actually called me in today and he said to me, 'your performance is going down' but I said to them, what do you want me to do?" (Ryan).

Those who were informed that it was allowed for them to be around any time said that it was a source of relieve for them because seeing their loved ones any time they wished lessened their worries. For example, one of them said:

> *"…they say we can come to visit anytime. It is good for us because we can see him and spend all the time with him. If you see him you feel better, they allow us to even sit next to him, there is nothing we do or say with him all the time because of the state he is but it makes a difference to see him and you don't worry and say mmm I wonder how he is now" (Violet).*

To some, it made them feel better to see their loved one still breathing and alive. One of them stated:

> *"I would wish to come in any time just to see him and be there with him all the time, even if I am not doing anything. It makes us feel better to see him still breathing and alive. When we are at home we just think what is happening now, how is he now? We think all the time, but when we are here we feel better and we can talk to him and say to him not to worry, we say we wish you well, you know such words of encouragement"* (Jack).

Some of the study participants mentioned that every few minutes they spend with them were most precious as they were not going to be able to see them again forever. One participant mentioned:

> *"…losing a loved one is painful and every extra moment spent in the last days of my dad will count to all of us as family and so we will maximize our togetherness knowing that these might be his last days with us, so really, every second and minute we spend with him is worth and it will remain in our memories even after he goes"* (peter).

Their presence also as families strengthened the bond between them and the patients and enhanced satisfaction towards the care of the patient as expressed by one of them as follows:

> *"They only told us now that we can come in anytime to spend time with him if we wish. This will be good for us just to share our last moments and bond together, even though it doesn't take away memories and thoughts of going to lose a loved one but still you can see that he is well taken care of and does not suffer in anyway" (Ryan).*

Although the majority of the families wanted to visit any time as long as they want, a few families had different opinions regarding visiting time. They indicated that they visited for a very short time and they were satisfied with that. One of them had this to say:

> *"…we even come to visit him and we could not stay let's say for more than 30 minutes. I don't see the reason for staying for long because if you come to visit, you just see how he is looking and we don't even speak to him because he cannot speak, he cannot see or open his eyes, may be sometimes it doesn't even take 10 minutes to be with him"* (John).

Another one said:

> *"…it takes us an hour and a few minutes and I will be fine because I will see what is going on and what is taking place there and then I will go home and come the following day to check how she is doing"* (Dave).

In order to reduce the stress levels of families of ICU patients, families should be allowed to visit the patient any time (Davidson, et al., 2007:608). Similar to the findings in this study, no informant felt prevented from being close to his or her loved one in the ICU in a study by Fridh et al. (2009b). These authors report that the families felt worried and tense, feelings that persisted even when they were not at the patient's bedside. The only way to overcome their worry was to go to the hospital because when they were together with their loved one, the focus shifted from their own emotions to concentrating on the patient. When the care time was short, it was experienced as very frustrating to have to go to the waiting room instead of being allowed to be close to the dying person. Precious minutes were wasted in the waiting room while the patient's condition deteriorated rapidly (Fridh, et al., 2009b).

The majority of the families interviewed in this study wanted an open visit to their dying loved one. Although the participating hospitals allow such families to visit any time they want, other families were not aware that they were allowed to come in any time. The reason may be they were not informed during their counselling session or after the decision of not for resuscitation was made that they can come in any time. This means that the staff does not direct or do not give full information needed by the families as some just found out during the interview that they could come in any time whereas some found out a day or two after the decision had been made. They had been visiting only at allocated visiting hours and this frustrated them a lot as they were always thinking and worrying about their loved one while they were at home. A few participants expressed that they only needed a few minutes to see their loved one and they were satisfied. They did not see the need of staying for long as they had nothing to do with the patient. This may be due to lack of guidance from ICU staff on what the family should to do while at the unconscious patient's bedside.

3B.9.2 Being present till death

Although some family members were afraid to stay with their loved ones till the last minute, some were willing to stay and not to let their loved ones die alone. Being present was supported by most participants. They said that it was not comfortable to stay and see the patient suffer and die but they were willing to accompany them and not abandon them till the end. One of the participants said that he asked the nurses to let him know in case he won't be in the hospital so that he can be present when his father died. This enabled him to perform his last ritual which is a belief in the Muslim religion. He had this to say:

> *"…it is good because the ICU is allowing us to come in any time. Due to this I will get access to perform my last respect to my father before he dies by holding his hand doing a prayer, because we believe if you pray and the dying person can hear, or if his last sentence is a prayer, then it means he is forgiven and granted paradise"* (Peter).

Another participant whose uncle was on palliative management said that as a representative of the family, she was advised to bring the immediate family who were staying far away from the hospital if possible so that they could be with the patient during his last days. She said:

> *"…they advised me to bring the wife and the kids, they must come in and stay with him until they are satisfied. I believe that if a person must go he must not go alone, he mustn't be alone, if he wants to die, let him die in dignity, but if she is not willing I will create time and come and be with him because he is my uncle"* (Maria).

To some being present was important so that they could make peace with the patient and satisfy the ancestors as stated by one of them:

> *"…it is good for him (patient) because he also don't stay alone. And I am sure even if he cannot look or speak he can sense that someone is there for him and we care and he is not lonely. Again because this may be our last times to see each other, it is good to make peace with one another (pauses). Maybe if I did wrong to you I can come and say I am sorry so that you can leave in peace otherwise, the ancestors may not be so happy"* (Violet).

The same participant also wanted to be present till the end so that she could talk to the spirit and collect the same spirit to appease the ancestors. She said:

> *"…it is a little bit uncomfortable to see him suffer and to watch him go, go, go until he is no more but when he dies, the soul will come out and it will just sit by his side, it will not go anywhere because it is waiting for us as family to do what we have to do. We must talk to it and send this soul to where it belongs and then we are at peace to know that everything is done in the correct manner"* (Violet).

Some of the study participants needed to stay with the patient as they thought they might have something to say that can enable the patient to die peacefully. For example one of them said:

> *"I am willing to stay with him because I may have something to say or tell him that can help him to die peacefully. Watching him die would be a very painful time but just because it is a precious and last time to see him, I will stay by him"* (Rachael).

Some of those that were afraid to stay did not know what to do when they are in the room with the patient. One of them said:

> *"I am afraid because I am afraid to end up with err, no I am afraid what if the person can die? What am I going to do? maybe someone will just call you and say she has passed away than to stand at her room and look at her very sick and suffering and then die"* (Pinky).

Another one said this concerning being present till death:

> *"…It is hard for me to stay until she dies but I can come and check on her for a few minutes and then go because I am not comfortable when I see someone who is almost dying or dead"* (Dave).

The findings in a study by Kirchhoff et al. (2008:119) showed that the information given to the family members did not only prepare them on what to expect in the process of dying and death but it also allowed them to make a more informed choice about being present at the patient's bedside. Being absent at the time of patient's death may represent anger or guilt on the part of family members (Kjerulf, et al., 2005). After receiving information of what to expect, some participants chose to be present while some chose not to be present in the room when their loved one died as they understood that the signs of impending death outlined in the intervention message might leave them with unpleasant memories (Kirchhoff, et al., 2008:119).

In another study by Fridh et al. (2009b:114) during the vigil, the close relative held the loved one's hand and tried to establish contact by talking to him or her. Many participants described being convinced that even if seemingly unconscious, he or she was aware of their presence and several had been encouraged by staff to talk to the dying person. As stated by Fridh et al. (2009b:115) being together with the dying person and other family members was of central importance. As the days appeared limited, it was essential to make the most of the short time that remained. Unlike the findings in this study, the nursing staff formed part of the group with whom they shared their experiences. When it came to facing death, families were

extremely sensitive and dependent on having someone to lean on. The staff members' tactful presence and support was described as much appreciated by many participants.

In this study, the majority of the families that were interviewed said that they were willing to stay with their loved till death. A few of them were afraid to stay by the patient's bedside till the end. Those that stayed till the last minute valued their presence as it meant not letting their loved die alone, not abandoning and more so it was their last opportunity make peace with one another and perform some rituals so as to allow the patient to die peacefully. It is speculated that all participants were not given information in preparation of what to expect during the dying process of their loved one. Those that stayed willingly chose to stay whereas those that were afraid to stay did not know what to do at the patient's bedside and what to expect. It would have been easy for them to make a choice of staying if someone told them what to expect in the process and what to do when at the patient's room. The presence of a nurse with them in the room offering support would also have played a major part in their choice to remain by their loved ones room till death.

3B.10 SPIRITUAL SUPPORT

A summary of the fifth and last major theme including its sub-themes has been provided in **table 3B.7** below.

Table 3B.7 Summary of the fifth theme and its sub-themes

MAJOR THEME	SUB-THEMES
3B.10 SPIRITUAL SUPPORT	**3B.10.1** Prayers to the patient **3B.10.2** Religious leaders

The section below will provide a detailed discussion of this major theme and its sub-themes.

Spiritual support was one of the main themes that emerged. All participants in this study valued religion and the importance of prayers in their lives and especially during their relatives' critical illness. They did pray and at the same time, they brought a religious leader to pray for the patient in the ICU.

Prayers including the presence of religious leaders will be discussed below as sub-themes arising from this theme.

3B.10.1 Prayers to the patient

All families prayed for the patient both in the ICU and while they were at home. Even though they did not receive this support from the ICU staff as a means of support, they did the prayers alone as families. One of the participants said:

> *"Spiritually, I will say not spiritually yeah, it is individual because I have not seen this service provided to us as family or to the patient, we just pray for him as a family*" (Maria).

The families had hope that prayers could change the patient's situation. They believed that God can do wonders as he knows better about the patient's life than the nurses and the doctors. One of the participants had this to say:

> *"we prayed a lot, and according to my Christian belief, I believe that in as much as nurses and doctors are doing their part, God is doing His part to bring about a divine healing"* (Jane).

> *"…we believed if we can pray God can answer our prayers and we have strong faith that God will answer and heal our mother"* (Pinky).

Another one said:

> *"I used to ask God to give the doctors powers to heal him (OK) yeah, even though we did not bring a reverend to pray for him we still had private prayers as family"* (John).

And:

> *"You never know things might change depending on whether God will want to give him another chance"* (Peter).

Apart from believing that prayers can change the patient's condition, it was also believed by the families that the patients were communicating with their God while they are in the ICU. This as mentioned by one of the participants needed to be boosted by the family through giving the spiritual care to the patient (praying) as this might be the only thing the patient needs before he dies. She had this to say:

> *"He is communicating with his God, so we as a family have never stopped. We must boost him by giving that spiritual care. Sometimes he needs a prayer, just a prayer, maybe he can just be happy and he can say now I can leave because I have got what I wanted. So if the nurse do give us time for that spiritual care we will just pray and then we will relieve this person and he can rest in peace. Sometimes they don't go; they just need that spiritual part" (Maria).*

The acknowledgement of the patient's and families' spiritual needs in end-of-life is associated with greater satisfaction (Gries, et al., 2008) and they should be assessed by the health care team (Davidson, et al., 2007:612). Similar to the findings in this study, lack of ICU team participation in spiritual support has been reported elsewhere by Ott (2010:77) who states that those who care for dying patients in critical care are often confronted with their patient's spiritual concerns but this spiritual issue makes them uncomfortable as they feel unprepared to address it.

Spirituality may provide a platform for family members to express themselves, feel comforted and to cope with death (Gries, et al., 2008). The findings in this study are similar to the findings by Wiegand (2008) whereby families prayed that their family member would prove health care team wrong and improve. On the other hand, religious practices play an important role in preparing for death. Such rituals, which include prayer, chanting and sacred texts can provide meaning, security, solace and ease the passage of dying (Carey & Corosgove, 2006).

All participants interviewed in this study believed in religion and they all sought solace in God. Even though spiritual support should form part of nursing care at EOL, none of the study participants received this form of support. This might have been due to unpreparedness of the nursing staff in carrying out such a task as this may not be a common or routine nursing task in this setting. Nevertheless, families continued to pray for and with their loved ones alone.

3B.10.2 Religious leaders

Where possible, families approached their religious leader to come and pray for the patient. This gave much support to the family as well as to the patient. The families got words of encouragement from the religious leader and peace of mind. They also got hope from the religious leader about the miracles and the possibility that the patient may get well again through God's power. This was explained by some of the participants as follows:

> *"I believe God, and I and if he says he will make a miracle then he will make it. I did speak to the father of the Catholic in my church and we prayed over and over for her recovery and we believed that he is the answer to anything and the healer"* (Gloria).

> *"…our plan is to bring a pastor to pray for him"* (Jack).

> *"I actually wished to bring some elders who are also his best friends from my church to pray for him but they are far away at home in Natal. But I did call them and they said they are going to be with us throughout and support us even if they are not here physically, but they said they will always remember us because we really need them at this point to make us strong in faith"* (Peter).

Spirituality is an essential element in creating a peaceful death (Kruse, Ruder & Martin, 2007) and is associated with greater satisfaction (Gries, et al., 2008). Similar to the findings in this study, a study by Longden (2011:135) also found out that for parents who belonged to a religious faith, their leaders provided significant emotional support and a religious perspective before and after the death.

Some families sought support from their church leaders as this was seen as an important source of encouragement and support. Despite offering prayers alone, families sought support from their church leaders probably because they trusted that he would pray for the sick to get healed and even if healing was not possible, the patient would die peacefully which would create a sense of satisfaction to the family.

3B.11 CONCLUSION OF THE FINDINGS

Although these findings represent the perspectives and experiences of a limited number of families, the statements of participants in these interviews provide an important understanding into the families' opinions regarding end-of-life care in the ICU. Their descriptions raise a number of important issues that are of significance in the nursing care of families and patients at end-of-life. Both negative and positive aspects have been raised by the families as to what impresses them and what needs to be improved upon so as to ensure adequate support and quality end-of-life care to them and to the dying family members.

Communication and receiving information was one of the important need raised by all family participants. Even though they all needed to be given information regarding their critically ill family members, they were not satisfied about how this was done, as they felt they were not given all the necessary information they needed. Due to inadequate information, the families felt like they were left in darkness most of the time. In order to obtain answers to their questions, they had to ask. They needed a daily report about the patient's status but this was not available. It was frustrating when they wanted to ask, the doctors were busy and the nurses would not or did not want to divulge the information. The families had to wait for the doctor and sometimes they had to go home without getting the information they needed to know.

It was also confusing when the families found different staff members caring for the patient giving contradicting information. This not only raised some mistrust but also portrayed a lack of unity and communication among the staff. Directions as to what to expect and what to do from the time when a decision of "not for resuscitation" was made till death was not available for the families. In such instances, families were left to wonder what to do and how to do

things while they waited for the death to occur. It is important for intensive care units to ensure that families of patients who die in the ICU are provided with consistent information, attention, and access to both the patient and health care professionals.

Another significant issue that emerged from the interviews was concerned with emotional support. All families expressed emotional disturbances and expressed the need for support at such a difficult time in their lives. Hope was common in all families and, despite being told about their relative's poor prognosis, they still had hope that a miracle would happen and that the patient would get well. This could indicate that the families had not or had to come to terms with the situation gradually. In spite of the outcome, the families wanted to be reassured that their loved ones would be kept as comfortable as possible in terms of pain management and hygiene. They all acknowledged that their family members appeared clean and comfortable. One concern raised was noise from the staff as families thought this could have caused discomfort to ICU patients as much as it was to them.

The reception to ICU was considered by the majority as inadequate. Patients' families expected hospitality and empathy but this was not provided by all the nurses. In order to decrease their stress level, families mentioned that they needed someone to talk to as well as to encourage them. Ideally, nurses should have been available for these families to provide emotional support and information till the end. However, it was reported that the nurses were not always in the patients' rooms. Frequently, when the nurse came to the room, she took a few minutes to attend to the patient and left again and (when she could talk to the family) this would be done hastily. This behaviour from the nurses made families feel unwanted. This raises the need for the ICU team to continuously prepare and support the families throughout the time the patient is in the ICU so as to reduce the level of stress and uncertainties. It also implies that nurses should be assisted to develop and refine their communication and interpersonal skills and given support for their interactions with family members.

The other major finding from the interviews was the lack of family involvement in decision making and direct patient care. All families wanted to be involved in the decision making process regarding the care of their loved. Unfortunately, this was not done as they were often

told about the decisions that had already been made rather than being involved in the decision making process. The families felt they should be included in the whole process as they are in a better position to know the patient's preferences than the ICU team. They also felt that they were in a position to advocate for the patient. Mostly, they felt as if the decisions came from the physician and neither the nurse nor the family could object since, once the decision was made, the care was steered in that direction.

The majority of the participants wished to be involved in the direct care of their loved one. Although this was their wish, the settings where the research was done do not allow families to participate in patient care in the ICU. The reason behind this could be that nurses are afraid that family members can make mistakes that could be harmful to the patient and they, as nurses could be held accountable. Nevertheless, families expressed the need for supervision and nurses' presence if they were able to assist with caring for the patient so that they can know what to do and what not to do. Involvement in direct patient care could be of importance to the families as it will allow them to be close to the patient during the last moments and it might enhance their satisfaction towards the care and comfort measures offered to their dying relative.

A further issue that emerged from the interviews is the need to access the patient at any time. Most families expressed the need to be with their ill family member whenever they wished. Visiting time for families of patients at end of life is always open in these settings. It appeared that some families were not informed about this benefit. To them waiting from one visiting time to the next one was too much as they kept thinking about what could be happening when they were away from the patient's bedside. Being at the hospital reassured them as they were able to see the patient still alive. It could be necessary for ICU team to give full information and to encourage visiting and its importance and what they should do as this could encourage even those who never wanted open visits to visit more often.

Finally, spirituality was another aspect that emerged from the interviews with the families. All families valued religion and the support from their religious leader as a form of support during this difficult time. Even though they did not receive such a support from the ICU

team, they all prayed for the patient and, at the same time they approached their spiritual leader to encourage them and to pray for the patient. Spirituality was viewed as a source of hope to recovery, and when recovery was not possible, a way of making peace and allowing the patient to die peacefully in a dignified manner.

In overall, the findings from the experiences of family members regarding end of life care in the ICU generally reflects poor nursing care to both the families and their dying family members. This is due to the fact that negative experiences shared by the families outweighed their positive experiences, as most families were not happy with the care they received while their family members were at the end-of-life in the ICU.

3B.12 SUMMARY

This chapter presented the methodology and the findings from the interviews with family members. Biographic information of the participants, discussion of major themes and sub themes arising from the interviews including the conclusion of the findings and a summary has also been provided.

The following chapter presents the methodology and discusses the major findings of the experiences of critically ill patients towards comfort care in the ICU.

CHAPTER 3C
EXPERIENCES OF CRITICALLY ILL PATIENTS ON COMFORT CARE

3C.1 INTRODUCTION

In the previous chapter, research design, methods and the findings and discussion of the themes that arose from the family members concerning their experiences of End-Of-Life (EOL) care were presented. This chapter which relates to step 3 of stage I presents the research design and methods including the findings and discussion of the major themes that arose with regard to the experiences of critically ill patients about comfort care in the ICU. Biographic information of the study participants is also presented followed by the discussion of the findings, a brief conclusion of the findings and a summary. Because they have had recent personal experience of being nursed in an ICU, patients' experiences make them 'experts' on ICU care although not EOL care. **Figure 3C.1** provides the summary of the presentation of this chapter.

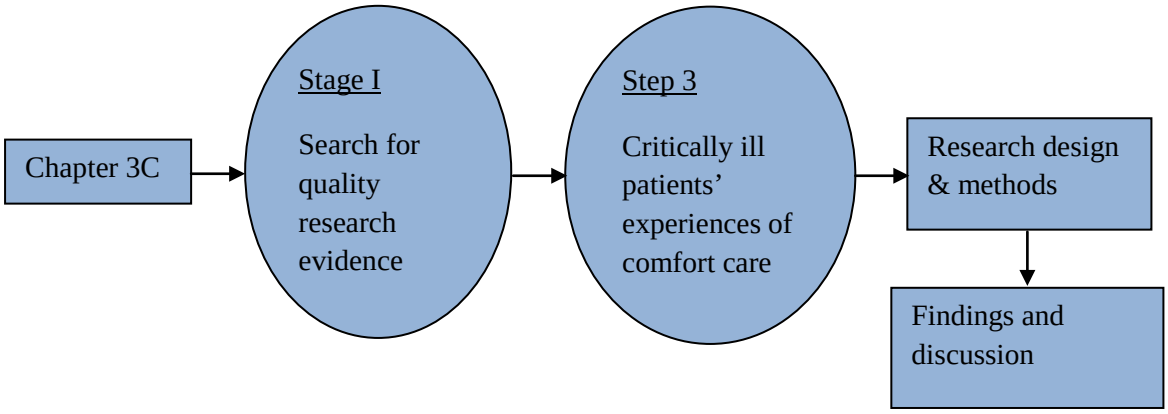


Figure 3C.1 A summary of the presentation of chapter 3C

3C.2 RESEARCH DESIGN

An exploratory, descriptive, qualitative design was used to describe the experiences of critically ill patients on comfort care.

3C.3 RESEARCH METHOD

3C.3.1 Target population

A target population refers to the entire set of individuals who meet the sampling (Burns & Grove, 2007). The target population for the critically ill patients included all the patients who were admitted to critical care units at the selected sites in the three hospitals, from May, 2012 to October, 2012, had a predicted mortality of above 50% within the first 24 hours of ICU admission and had been discharged to the ward or a step down facility.

SAPS II is well known and used in prognosis prediction, description of the morbidity of a patient when comparing the outcome with other patients and description of illness severity. Predicted mortality was calculated using SAPS II calculator which converts SAPS II scores into predicted mortality in percentage (http://clincalc.com/IcuMortality/SAPSII.aspx). SAPS II calculated values were used in this study because SAPS II is commonly used in the ICU and has been determined to estimate mortality risks with considerable accuracy (Can, Yagci, Tufan et al., 2008). Those patients that had high predicted mortality rate were purposively selected as they were regarded as severely ill hence their likelihood of death and need for comfort care.

SAPS II (refer to **appendix O**) by Le Gall et al. (1993) comprises 15 items and each item is awarded between 0 to 26 points. The SAPS II score records the worst value of each physiological variable during the first 24 hours of admission. The range of scores is 0 to 163 and its predicted mortality is between 0% and 100% (http://en.wikipedia.org/wiki/SAPS_II).

3C.3.2 Sampling and sample

Purposive sampling involves the conscious selection of certain subjects by the researcher (Burns & Grove, 2007:344). This type of sample is based entirely on the judgement of the researcher, in that a sample is composed of elements that contain the most characteristics, representative or typical attributes of the population that serve the purpose of the study best (de Vos, et al., 2011:392). A non probability purposive sampling method was used to select critically ill patients so as to elicit their experiences of comfort care in the ICU. The patients were selected until a point of saturation of themes was reached. Saturation point was attained after fourteen (n=14) participants were interviewed. In total, a sample of sixteen (n=16) participants was interviewed. ICU patient charts were used as a sampling frame. The patients who met the inclusion criteria were approached for their consent to participate in the study after they were discharged from the ICU.

Inclusion criteria for the critically ill patients included:

- Those who had a predicted mortality of above 50% within the first 24 hours of ICU admission and survived until discharge from ICU.
- Those who could understand and speak English as the researcher is not sufficiently proficient in the many vernacular languages nor in the many African regional languages used by patients in these three hospitals.
- Patients who had been discharged to the ward or a step down facility (minimum of four days) from either multidisciplinary, trauma or cardiothoracic ICUs in the three hospitals.
- Those who were conscious, comfortable and in stable condition at the time of interview based on stable and-within-normal limits of hemodynamic parameters and were able to communicate.
- Those 18 years and older provided written consent to participate had been obtained

3C.3.3 Data collection procedure

After obtaining permission to conduct research from the Postgraduate Committee of the Faculty of Health Science University of the Witwatersrand, Gauteng Department of Health,

Human Research Ethics Committees of both the University of Witwatersrand and Pretoria, the chief executive officers of the three hospitals and the clinical heads including the unit managers, the researcher purposively selected patients regarded as 'experts' as they had recently experienced ICU care though not EOL care.

A prospective record review of the critically ill patients on admission to ICU was completed prior to selection of the patients. Using SAPS II instrument (refer to **appendix O**), the researcher identified forty patients who had a predicted mortality of above 50% during the first 24 hours of ICU admission. This cut off limit was chosen as some patients were expected to die before they were discharged to the step down facility based on their illness severity and complications. Thereafter, the researcher followed up the patients until discharge from the ICU. Those who had a predicted mortality of above 50% and died were excluded in the study. Once they were discharged from the ICU, the researcher approached the patients that met the inclusion criteria in the step down facility for their consent to be included in the study.

Those patients who volunteered to participate were given an information letter outlining the purpose of the interview and a consent form for inclusion in the study (refer to **appendices P** and **Q respectively)**. The researcher then met separately with each potential participant who consented to participate in the study at their bed side taking care to ensure privacy, during their own time for the interview. An assurance that all the tapes will be kept in a locked cupboard and data kept safe under password protected computer was made to all the participants.

As suggested by Creswell (2007) and Kvale (2009), the introductory phase of the interview involved explaining to the participants the purpose of the study, their expected role, clarifying the amount of time needed to conduct the interview and the use of a tape recorder. During this time, a separate written consent was obtained for the use of a tape recorder (refer to **appendix R**). Before commencing each interview, each participant was requested to provide a pseudonym of their choice to be used by the researcher so as to ensure their anonymity and confidentiality. In order to create a relaxed and suitable atmosphere, the interview process

started in an informal and friendly manner. Bearing in mind that English was not the participants' first language, and despite the fact that they were purposively selected because they could understand English, the fluency was not possible for some participants. Due to this, the researcher tried to use simple English as much as possible while asking the questions during the interviews taking care not to alter the meaning of the questions that were intended to be asked.

Data were collected by use of semi structured interviews. Semi structured interviews are used in order to gain a detailed picture of a participant's beliefs about, or perceptions of a particular topic (Creswell, 2007). This method of data collection gives the researcher and participant much more flexibility and the researcher is able to follow up particular interesting avenues that emerge in the interview while the participant is able to give a fuller picture (de Vos, et al., 2011:351). An interview guide (refer to **appendix S**) was used so as to ensure that all questions were covered and, at the same time, participants were encouraged to talk freely about all the questions on the schedule (Brink, et al., 2008). Probes were also used to elicit additional information from the participants (Kvale, 2009).

To maintain the focus of the study, all of the participants were asked the same questions. Preceded by the following introductory comments, the participants were asked the question below during the interview session: "Thank you so much for offering to help me. I want to stress that I am grateful for your experience and expertise but the actual discussion on comfort care in ICU does not apply to you personally or your family member because you are now out of the ICU".

"What were your experiences of nursing care while you were in the ICU"?

The interviewee was allowed to direct the flow of information with the researcher focusing it by use of more focused and probing questions and interviewing techniques such as paraphrasing, summarizing, minimal verbal response, non verbal response and clarification (Kvale, 2009; de Vos et al., 2011:345).

To ensure that all the information was recorded for verbatim transcription, all the interviews were tape recorded (Kvale, 2009). Field notes, which are written accounts of the things that the researcher hears, sees, experiences and thinks about in the course of the interviewing were written during or immediately after the interviews and inserted at relevant points during transcription so as to enrich the tape recorded interviews (de Vos, et al., 2011).

It is believed that after a gasp of relief, some interviewees may bring up topics that they did not feel safe raising with the tape recorder on (Kvale, 2009:56). Because of this, once the tape recorder was switched off after each interview, each of the participants was allowed to express their feelings about the interview as a means of debriefing. Any new information that arose was written down under field notes and later transferred to the relevant section during transcription. Each interview lasted between 30 minutes to 1 hour.

Data analysis begun straight away after the first interview and continued in parallel with ongoing data collection (Brink, et al., 2008). In order to obtain greater richness of data in this study, sixteen (n=16) participants were interviewed. Data collection and data analysis continued in parallel until it was clear that no new information that added to the understanding of the categories and themes emerged from the interviews hence data collection was terminated (Creswell, 2009).

3C.3.4 Data analysis

In qualitative data analysis, the researcher reflects on the possible meanings and relationships of data (Brink, et al., 2008). This type of analysis is described as a 'hands-on' process during which the researcher becomes deeply immersed in the data, examines and interprets the findings for the purpose of discovering underlying meanings and patterns of relationships (de Vos, et al., 2011). Data analysis in qualitative research is an ongoing, emerging and iterative process (Henning, Van Rensburg & Smit, 2004; Polit & Beck, 2012).

Transcribing the interviews from an oral to a written mode structures the interview conversations in a form amenable to closer analysis and is in itself an initial analysis (Kvale,

2009:94). The transcripts are then analysed either manually or with computer programs (Polit & Beck, 2012). The first step of data analysis in this study was the verbatim transcription of the tape recorded interviews. Pauses, sighs, silence, crying and other non-verbal actions were indicated in brackets in the transcripts. Data were then manually analysed following Tesch's (1992) eight steps of data analysis. These steps were applied as described below.

On completion of transcription, the researcher checked for accuracy by simultaneously reading and listening to the audio-taped interview and making necessary corrections. The process of proof reading enabled the researcher to be immersed into the data, to become familiar with the interview and to get a sense of the whole. While reading through the transcripts the researcher wrote down any ideas that came to mind. The researcher then picked the most interesting transcript and read so as to seek the underlying meaning of the information described by the participant. During this process the researcher made notes on the margin of the transcript. This process was repeated for the rest of the transcripts. Once this was done, a list of all topics was made and thereafter, similar topics were clustered together. The emerging topics were abbreviated as codes

In the next step, the researcher wrote the codes next to the appropriate segments of the text. The most descriptive wording for the topics that emerged was identified and turned into categories. In this case, the researcher underlined the main emerging themes and placed the code in the margin next to the theme in the text. Using own words and a different colour of pen, the researcher summarised the themes as key words at the margin of the transcript. Reading the transcripts repeatedly strengthened the researcher's familiarity with the interviews and enhanced understanding of the meaning of the interviews. At this point, the researcher started to link the emerging themes to theories and identified the developing patterns.

In addition, all the major themes and sub-themes were put together in a table format and all the data belonging to each of these were put against them. The data were labelled according to the participant's pseudonym and the page number of the transcript to enable easy revisit to the original transcript. In order to ensure that the themes that emerged in this study were a

reflection of comfort care in the ICU, two co-coders were requested to check the themes that emerged in this study. The co-coders did not make any alterations or additions to the themes that were already identified by the researcher. These co-coders were considered suitable by the researcher because they understand the topic under research, have an experience in critical care and are currently pursuing their postgraduate degrees in critical care nursing. Finally, the researcher re-coded the existing data to reduce the categories/themes. For auditing purposes, refer to **appendix T** for an analyzed transcript.

3C.3.5 Pilot study

Before the commencement of the main study, the interview guide and interview process was piloted on one patient. This helped the researcher to recognize and address some of the unforeseen problems that could arise in the course of the study (Brink, et al., 2008). This may include making adjustments to the methodology, instruments and analysis to ensure that they are adequate and appropriate (de Vos, et al., 2011). The researcher conducted a pilot study in this study so as to refine the technical aspects of tape recording, transcribing interviews and to improve her interviewing techniques. An evaluation of these skills was sought from three fellow students at the nursing department. The interview guide was found to be feasible hence no changes were made. Since there were no changes made, the pilot interview was included in the real study.

3C.4 DEMOGRAPHIC INFORMATION OF THE PATIENT PARTICIPANTS

Table 3C.1 below shows the summary of the demographic information of the patient participants in this study. Out of 16 patient participants interviewed in this study, the majority were female (56.25%; n=9) whereas the minority were male participants (43.75%; n=7). Black participants dominated in the study (87.50%; n=14) with white participants accounting to 12.50% (n=2) of the study participants. The ages of the participants ranged from 24 to 64 years. The patients' length of stay in ICU ranged between 4 days to 15 days. SAPS II scores ranged between 52 to 64 scores with the lowest predicted mortality being 50.7% and the highest being 75.3%.

Table 3C.1 Demographic information of patient participants

No	Pseudonym	Gender	Race	Age (Years)	Days in ICU	SAPS II score (Predicted Mortality %)
1	Patrick	Male	Black	41	7	56 (59.8)
2	Jacky	Female	Black	29	12	52 (50.7)
3	Lilly	Female	Black	27	8	60 (68.1)
4	Mpo	Female	Black	59	7	58 (64.0)
5	Annie	Female	Black	41	5	55 (57.5)
6	Cindy	Female	White	56	4	57 (61.9)
7	Niki	Female	Black	58	6	59 (66.1)
8	George	Male	White	26	11	53 (51.3)
9	Ruby	Female	Black	53	6	64 (75.3)
10	Tim	Male	Black	32	7	56 (59.8)
11	James	Male	Black	24	15	54 (55.3)
12	Duke	Male	Black	48	5	52 (50.7)
13	Lucy	Female	Black	53	7	53 (51.3)
14	Slu	Male	Black	24	8	55 (57.5)
15	Sharks	Male	Black	64	6	62 (71.9)
16	Zodwa	Female	Black	37	9	53 (51.3)

3C.5 FINDINGS AND DISCUSSION

Prior to the discussion of the findings obtained from the above critically ill patient participants, a summary of the themes and sub-themes that emerged from the interviews are presented in **table 3C.2**.

Table 3C.2 Themes and sub-themes emerging from patient participants

MAJOR THEMES	SUB-THEMES
3C.6 BEING IN SOMEONE'S SHOES"	**3C.6.1** Sense of compassion **3C.6.2** Reassurance **3C.6.3** Respect of privacy **3C.6.4** Existence of pain **3C.6.5** "Lying just like a parcel" **3C.6.6** Disturbing noises **3C.6.7** Constant anxiety
3C.7 COMMUNICATION	**3C.7.1** Explanation of interventions **3C.7.2** "Dealt with like a specimen**"**
3C.8 TRUST	**3C.8.1** Trust in them
3C.9 PRESENCE	**3C.9.1** Nurses' presence **3C.9.2** Family presence **3C.9.3** "You don't want your family to know"
3C.10 RELIGION AND SPIRITUALITY	**3C.10.1** Personal prayers **3C.10.2** Prayers from nurses **3C.10.3** Prayers from religious leaders

In the next section, the findings will be described in detail and illustrated by means of verbatim quotations from interviews. Each theme, its related sub-themes followed by citation of relevant literature will be discussed in detail.

The first major theme to be discussed will be "being in someone's shoes". This major theme including its linked sub-themes has been illustrated in **table 3C.3** below. Following this summary, a detailed description of each of these sub-themes will be presented.

Table 3C.3 Summary of theme one and its linked sub-themes.

MAJOR THEME	**SUB-THEMES**
3C.6 "BEING IN SOMEONE'S SHOES"	**3C.6.1** Sense of compassion **3C.6.2** Reassurance **3C.6.3** Respect of privacy **3C.6.4** Existence of pain **3C.6.5** "Lying just like a parcel" **3C.6.6** Disturbing noises **3C.6.7** Constant anxiety

3C.6 "BEING IN SOMEONE'S SHOES"

"Being in someone's shoes" is one of the themes that emerged from the interviews with patient participants. Participants mentioned that they needed someone who could meet their needs in ICU and this, could only happen if the nurse imagined, felt and understood their experiences the patients were going through and what actually it means to be in that position. As stated by Hofhuis, Spronk and Stel, et al. (2008), important to patients is the fact that nurses try to keep seeing them as human beings and as the centre of their attention in the ICU; meaning that they perceive that humane care is crucial. In another study, patients and families repeatedly noted the importance the ICU team treating the patient as a person (Nelson, Puntillo & Pronovost, et al., 2010:814). Several sub-themes emerged from this theme and they included: sense of compassion, reassurance, respect for privacy, existence of pain, "lying just like a parcel", disturbing noises and constant anxiety. Each of these sub-themes will be discussed in detail in the following section.

3C.6.1 Sense of compassion

A sense of compassion and empathy was one of the aspects valued most by the majority of the patient participants. To them, having a compassionate nurse meant that the nurse cared and regarded them as human beings. Participants had mixed experiences of compassion with some saying that the nurses were compassionate while others reporting that the nurses were not. For example two of those who said nurses were compassionate said:

> *"…nurses are not the same others are good and others are not good. There was one sister I liked her because she treated me so well, she treated me like her mum or her mum in-law. Otherwise,* the *care was good apart from the few nurses. But I must say they (nurses) must be courteous to their patients"* (Niki).

> *"…they were not rough; they always had a nice tone"* (Annie).

Those who felt some of the nurses were not compassionate said:

> *"…they should be compassionate and get humane for the sake of us patients"* (George).

And

> *"She didn't greet me when she came. She wasn't asking me if I am in pain or not and it looked like she didn't have the care like the others who had clocked off the duty. She could come in do her things and then go"* (Annie).

Some participants compared the approach the doctors use when they come into their room. It was stated that doctors tend to greet and ask about the patients' wellbeing in contrast to the approach used by the nurses. It was mentioned and believed that some nurses work for money while some actually care for the patients. One of them had this to say:

> *"…you can see if a doctor comes in, he asks you stuff first, how are you feeling, how are you doing? Did you pass stool? Not just like the nurse does…mm (Mr. so and so..mentions his name) I need to take blood from you and then go. All you want to do*

is do your job for pay and you don't care about, and who this guy lying here is. Their attitude becomes your attitude and you start swearing at them you know and it doesn't help. You wish you could put them in your shoes so that they can see what you are going through" (George).

Some patients expressed how rough handling and aggression displayed by the nurses indicated a lack of compassion. One of the participants said:

"…there was one (nurse) there who was very aggressive and it was actions and words. People (nurses) must be human and treat others (patients) nicely and improve on the compassion and love for the caring of patients" (Cindy).

"…others (nurses) were rough, don't greet they just come and start working. They open water and start to wipe you. They say OK hold that, I can't hold you have to pull yourself up and they say come, come. And when I vomit it makes them more cross. Sometimes they wrap you so hard and you feel much pain. I mean why can't they do it gently?" (Niki).

In-line with the findings in this study, patients in a study by Hofhuis et al. (2008) reported that human aspects such as compassion were considered important while in the ICU. When patients had the feeling of not being taken seriously or were approached with aggressive behaviour by the attending nurse, they reported feelings of fear, not being understood, not knowing what was happening or feeling that they were inhumanely treated. Patients in a study by Nelson et al. (2010:814) saw it as a measure of excellence for members of the ICU team to treat patients with the same care and concern they would give to a member of their own family, or at least to approach the patient as another's loved one.

The findings from the interviews with the patients revealed that majority of the patients did not receive compassionate care. This could be due to nurses' lack of empathy and understanding about the situation in which the patient is going through. The nurses' aggressiveness towards the patients and their rough handling could depict lack of humanity and a non-caring behaviour.

3C.6.2 Reassurance

Apart from general communication between the patient and the nurse, the majority of the patient participants mentioned that reassurance and encouragement was important to them. This is not only because it made them satisfied psychologically that someone cared about their wellbeing but it also made them feel better and gave them hope to recovery. Reassurance as reported came from both the nurses and the families. All patients wanted to hear these pieces of encouragement throughout their sickness. For example those who received reassurance from the nurses said:

> *"One sister (nurse) came to me and I was crying. She talked to me and she said, only God knows what he is doing with your life, when she finished I felt much better. Others were telling me that it is going to be fine, that I should not worry. I knew there was someone who was caring and they helped to save my life."* (Lilly).

> *"If the nurses do their jobs, if they make you comfortable, if they talk to you, if they nurture you it is enough. You need someone to tell you don't get worried you are going to get better, not just do whatever and get away from me"* (George).

> *"…the one sister (nurse) there could talk to me and say it is going to be well. Others could speak general things not really going into your emotions and uplifting your spirits"* (Cindy).

> *"…always talk to patients and encourage them no matter what they are going through because we are human beings. And even if we are patients we still need that human love and comfort. When they (nurses) talk to you that you must not worry, things will be alright then it makes you feel better"* (Ruby).

Two of the participants who received reassurance from the family said:

> *"I got so much strength from my friends, sister and brother. They were telling me it is going to be OK even the nurses and doctors were good they also did encourage me"* (James).

> *"My husband could talk to me and say it is going to be well and I should not stress and worry. Such reassuring words left me feeling better and made my sorrow less. I realized at least other people care about my wellbeing"* (Cindy).

Lack of reassurance as expressed by one participant was like being in a deep pit. He said:

> *"I wanted to be reassured, so the moment this is missing, then eer you…really like have fallen into a deep pit and you just want to get out of the pit and sometimes you wonder, am I really going to get out?"* (Patrick).

When asked whether she had any recommendations that could help improve comfort care in the ICU, one of the participants said that nurses should:

> *"…offer psychological care to patients in the ICU that you know what, it is going to be well, it is going to be OK and we are going to help you. All those pieces of encouragement because words of encouragement really are important. You can almost see a light at the end of a tunnel even if all you could see is death facing you"* (Jacky).

While reassurance was valued by patients in this study, it is evident that this is a common need in critically ill patients. Patients in a study by Hofhuis et al. (2008) perceived the nurses' encouragement, providing care and cheering them up as being lifesaving factors. The need for reassurance and psychological support of ICU patients by nurses has also been documented in literature (Papathanassoglou, 2010; Peris, Bonizzoli, Iozzelli, et al., 2011).

Psychological support and reassurance was reported to be an important aspect by the majority of the patients interviewed in this study. Although they regarded encouragement as important, this was not available most of the time. Apparently, this could mean that most nurses do not spend time talking to and encouraging patients. It could mean that all they do is their routine nursing care and they don't go an extra mile to reassure the patient serving as a source of emotional and psychological support.

3C.6.3 Respect of privacy

While most study participants wanted the privacy of their bodies to be maintained requesting that physical exposure be observed, others wanted their being to be treated with respect. Some wanted their life to be made private at all times. Exposure of their bodies meant that nurses did not regard them as important and did not uphold their dignity. For example one of them said:

> *"…a bit more respect for my body…they treat your body as though it is not something. They could open the doors without even having to close it and you would be exposed. One couldn't care so much about closing the curtains nicely for your privacy"* (Jacky).

Other examples of those who wanted their being or life to be respected and made private included:

> *"…you must treat the person (patient) with respect because I am not here because I am coming to enjoy myself but I come because I want to be treated because I feel the pain and I can't even move my body."* (Niki).

And

> *"…there are things that I would not like my family to know about my life. Families come to visit you and they go and tell the others. I just want my life to be private"* (Lucy).

The importance of patient's dignity has been emphasised in literature. For example, the findings by Nelson et al. (2010:813) revealed that many families were distressed to see patients exposed in open or glass-walled ICU cubicles, without efforts to shield private areas of the body from public view. In a study by Baillie (2009), respect was the most commonly used term relating to behaviour associated with dignity. Staff behaviour had an important effect on patients' dignity and related to interactions with patients and provision of privacy. Similar to the findings in this study, bodily exposure was regarded as a lack of privacy of the

body, which a third of patients identified as a threat to dignity with a few associating a lack of auditory privacy (whereby nurses spoke in loud voices about their private lives) with a loss of dignity (Baillie, 2009).

The findings obtained from the patients in this study indicated that patients value their privacy, both to their bodies and to their information. Ideally, it is the role of the nurse to respect and protect the patient's privacy. On the contrary, the findings from this study appear to imply that nurses did not respect the patients' privacy. An example given is the situation whereby the patient's body was exposed. In this case, the patient's dignity was not upheld and this means the nurses did not screen the patient's bedside while they performed their procedures despite of the availability of curtains and doors. The need of respect for patients' privacy is emphasised to every nurse during their education and reiterated constantly in literature. This means that not all nurses implement many of the important lessons learnt.

3C.6.4 Existence of pain

Pain related to the patient's illness and procedures was common in all study participants. For some, the pain was experienced as unbearable while for some, pain existed but it was manageable. Those who reported that they were in pain that was manageable had this to say:

> *"I can say it was well managed and they gave me morphine and some epidural pain killer which really helped"* (George).

> *"…the pain was there but they used to give me medication all the time"* (James).

> *"…there was not so much pain because they put a tube on me and the machine pumps in the medicine. It is not like I have to wait for the nurse to come and give me medicine, so really the pain was not much"* (Tim).

On the other hand, participants who said the pain was a lot had this to say:

"…there were times when it could really get so uncomfortable and they (nurses) were nowhere to be seen. They would take years to come and I would really get so frustrated, you are so immobile, in so much pain. I thought I am going to die. I could not talk and they cannot pick up that you are in pain unless you tell them you are in pain (closes her eyes and shakes her head)" (Jacky).

"The pain was the problem and that pain I was going through I thought no, I won't make it" (Niki).

"*…even that one (nurse) who was there with me I said I feel pain after they put urine catheter, and she said no, no, no, it is always like that. S*o apart from that pain I told you, really there was nothing much*"* (Duke).

Existence of pain while in ICU has been supported in a previous study in that patients recalled pain days after discharge from the ICU and stressed the need for frequent assessment for pain, and the administration of timely and effective analgesia (Nelson, et al., 2010:813). The appropriate management of pain has long been a problematic area of nursing practice and particularly a complex area in the ICU, where many patients are unable to verbalize their pain (Cade, 2008:288). However, the state of freedom from pain has been considered the most important thing by patients in other studies (Downey, Engelberg & Curtis, et al., 2009; Xie, Kang & Millls, 2009).

All patients interviewed reported that they experienced pain. Even though some of them had pain that was well managed by use of analgesics, a number reported that they had a lot of pain that they considered almost unbearable. Pain management promotes comfort in ICU patients and although this should be met, some patients' pain was poorly managed. Due to the fact that most critically ill patients are unable to talk either due to the nature of their illness or being intubated, most of these patients could not express themselves and report the existence of pain. Because of this, it is up to the nurse caring for these patients to assess and manage pain promptly. While some patients cannot express themselves completely, others can by using sign language or talking especially after extubation.

Nurses are responsible for the administration of prescribed as needed analgesia including the titration of analgesic infusions. In order to perform this task correctly, accurate clinical assessment of pain is required. Apart from physical assessment of existence of pain, various pain assessment tools such as behavioural pain scale have been validated and should be used in the assessment and identification of pain in critically ill patients.

Existence of pain in some of the study participants therefore could mean that either the nurses were slow to respond, did not assess pain, negated complaints of pain or did not inquire about the patient being in pain. The other reason might be that there was no prescription of analgesia in place and the nurse felt unable to act as the patient's advocate by asking the doctor to prescribe the analgesia. It is evident that the patients' level of pain could evoke memories of pain which could remain a psychological disturbance long after discharge from ICU. This was evident when, for example, Jacky who had been in ICU for 12 days expressed how much pain she was in while admitted in the ICU. Some said they thought they were going to die, meaning they experienced excruciating pain.

3C.6.5 "Lying just like a parcel"

All patients were very sick, bed ridden and fully dependent for days. They were dependent on nurses for most of the activities of daily living including personal hygiene. Their dependence expressed as "lying just like a parcel" by one of the participants indicates how helpless the patients situation was. To express their state of being helpless and dependent, two participants said:

> *"I was just like a parcel just lying there on the bed no move, no what…I hope I will be better very soon"* (James).

> "…when you are in ICU you are just like the person who is dead because you are hopeless, you can't talk or move" (Lucy).

Despite of being helpless and hopeless, all patients expressed that nurses made them clean and comfortable every day. Some of them said:

"Nurses were good because a patient is a patient, they used to pamper me and they know I have to bath, not like here in the ward where they sneer (sneers) if you say I want a bed pan" (Zodwa).

"I was very comfortable, very warm, nicely warm, clean, bath; sisters (nurses) were so lovely and warm" (Cindy).

"I was very very comfortable I was kept clean, I stayed in clean area, they covered me nicely and I was not cold they could rub my back every now and then" (James).

"They treated me very nicely; they were so patient to help me. I was clean and they washed me in the morning and they made sure that I was clean before the day starts" (Lucy).

Even though the majority of the patients were kept clean and comfortable, one of them reported that he was not quite comfortable in the ICU. He said:

"…it was hot, there was no aircon and I was sweating and I have got sores even now on my back" (George).

With the many changes that come with illness and therapies applied in the ICU, it is important to keep the patient 'look' as normal as possible (Elliot, Aitken & Chaboyer, 2012:105). Patient hygiene in the ICU is associated with benefits for patient's comfort and health outcomes (Coyer, O'Sullivan & Cadman, 2011). Supported in literature, personal hygiene is closely related to the patient's esteem and sense of wellbeing and, while the patient may sometimes be unaware of the nurses' efforts to keep them clean, this could be done for the sake of families as it may influence their perceptions of the quality of care the patient is receiving and the confidence they have in the staff's ability to care for the patient (Elliot, et al., 2012).

From the findings in this study, it is evident that all critically ill patients are helpless and fully dependent on the nurses not only for therapeutic interventions but also for activities of

everyday living which include personal hygiene and comfort measures. The majority of the patients were satisfied with how nurses kept them clean and comfortable all the time. This indicates that the nurses ensured that while upholding their patients' dignity, they never neglected the physical aspect of caring all the time.

3C.6.6 Disturbing noises

Some participants reported that it was noisy in the ICU. The main source of noise as mentioned is from the radio played by the nurses and the loud talks from the staff. This was reported to cause sleepless nights or stressful days and might have meant that nurses or other staff did not care. Some of them said:

> *"…other nurses make noises in the ICU with their radios on phones; they were playing music right at my room"* (Niki).

> *"24 hours you don't sleep, the staff are making noises, they talk a lot, they scream and shout, they make their own music in the phone"* (George).

> *"…the sounds from the machines, it was sounding like all the time and it becomes too much noise"* (Annie).

> *"…the place was a bit noisy from the staff and some machines were alarming and in that state, you cannot relax"* (Jacky).

Noise is just one of a number of factors that may disrupt the sleep of patients in the ICU and its source vary from ventilator noise, ventilator alarm, suctioning, pulse oximeter tones and alarm, telephone ringing, air conditioning, television, radio, banging rubbish bin or trolley noises, staff bleeps, talking (staff, nurses), visitors, fellow patients and general activities (Xie, et al., 2009:4). Similar to the findings in this study, these authors indicate that staff conversation and alarm seem to be the most disturbing noises for ICU patients' sleep. The findings in this study are also similar to those by Pugh, Jones and Griffiths (2007) whereby patients reported that staff communication is the most irritating noise whereas alarms were

perceived as disruptive. Hofhuis et al. (2008) also support these findings in that patients in their study reported discomfort due to the noise of loud voices and conversations between the nurses.

Some of the patient participants interviewed in this study mentioned that the ICU was noisy and uncomfortable due to the noise from the music, staff and the machines. Even though playing music on their phones could be considered relaxing to some of the ICU nurses, this was found by some of the patients to be irritating and disturbing as they could not sleep or relax with the presence of such noise. Patients also reported that staff were noisy. Although communication is normal and allowed, it means that the staff were communicating in loud voices which ended up being uncomfortable to the ICU patients. On the other hand, alarm setting on the machines is important in the ICU as it alerts the nurse in case there is a need for attention. This, to patients, it meant a source of noise. This could be due to the fact that patients don't understand why there are alarms and they might need to be informed that they will hear alarms frequently while in the ICU.

3C.6.7 Constant anxiety

Anxiety and worry were reported as common problems by the patient participants while in the ICU. As expressed by one participant, anxiety was felt especially when she was alone in the ICU room and the nurse was out of the room for long. For example, she said:

> *"…I was alone in the room and some nurses go away for long and you start to get anxious"* (Annie).

Another participant said that he was always anxious about who is going to nurse him when each new shift came. This is because he had received care from different nurses as a quadriplegic and while some handled him in a good way, others handled him roughly. He said:

"Some (nurses) were good because they know what to do but some don't listen to you. I was always scared about who is coming to the shift, is he or she going to listen to me? I was just worried about that" (Slu).

As confirmed in other studies, it has been reported that ICU patients are very sensitive to the attitudes and behaviours of staff, who may either increase their anxiety and vulnerability or make them feel more safe and confident (McCabe, 2004). In addition, the caring behaviour (described as sweet, nice, compassionate, showing interest) and continuous support, which was perceived to be inadequate in this study, has been shown to relieve the patients' fears and worries (Hofhuis, et al., 2008).

Anxiety was reported by most of the patient participants interviewed in this study. Worries were related to various aspects including: the illness, being left alone for long and the type of the nurse going to provide care among others. Being critically ill, attached to and surrounded by a lot of machines, it could appear that patients worried that something wrong would happen to them when the nurse is not around. Patients might have related their safety to the nurse being at their bedside thus nurses' presence would be a source of reassurance to them.

On the other hand, worries about what kind of a nurse will report in each new shift as reported by one of the patients could be attributed to the different kind of care or attention received from different types of nurses. Given the fact that there is no continuity of nursing care in these three research settings, it is apparent that the thought of having a new nurse in each shift becomes a threat to patients as they often start to think whether the nurse will be 'good' or 'bad'. The researcher would think that, when a patient meets several nurses, he or she starts to judge the level of care provided by each of them and some are regarded as 'good' and some as 'bad' nurses.

In **table 3C.4**, a summary of the second theme and its related sub-themes has been provided. After this, description of each of these sub-themes will be provided in detail.

Table 3C.4 Summary of the second theme and its associated sub-themes

MAJOR THEME	SUB-THEMES
3C.7 COMMUNICATION	**3C.7.1** Explanation of interventions **3C.7.2** "Dealt with like a specimen**"**

3C.7 COMMUNICATION

Communication is one of the themes that emerged from patient participants in this study. The participants valued communication between them and the nurses throughout their stay in the ICU. Even though they were not able to communicate at some point, they said that they could still hear and could even respond by signs. Two sub-themes associated with this major theme including "explanation of interventions" and "dealt with like a specimen" will be discussed in detail in the following section.

3C.7.1 Explanation of interventions

Majority of the patients felt that nurses should explain to them what needed to be done. Even though they valued explanations, it was not always done by the nurses as some of them went ahead with their activities on the patient without explanations. In some occasions, nurses did explain the interventions and procedures to the patients. Some of those who received explanations felt happy with the way nurses treated them. For example, some said:

> *"The nurses were talking to me and every time they gave me the injection they told me this injection if for whatever. If they wanted to do something they just tell me and I was happy with the way they treated me"* (Mpo).

> *"…they were talking to me they said good morning. They tell you when they are coming to do something to you. They say my name is so and so, I am going to do this to you, I am your nurse. They clean you they do everything and when she goes, she says goodbye"* (Ruby).

Those patients who reported that nurses did not offer explanations said:

"Communication was up and down; some stayed with me and were my favourites, talked to me and explained things. Some said I was troubling them and they would come and say I hear you are a trouble maker, today I am your nurse" (Slu).

"I needed somebody to explain to me what was going on, what has happened to me, why give me this medication. They didn't communicate to me all the time. If you come and speak to me in a language that I don't understand, then it becomes a problem because we don't understand each other. Somebody would come and they just do whatever and not even say a thing to you or smile and that already shows how they don't care about the little stranger in their hands" (Jacky).

Similar to experiences of some of the patients in this study, explanations and instructions were perceived by patients in a study by Hofhuis et al. (2008) as being reassuring, resulting in less fear and insecurity. Patients were more aware of what was going to happen and this assisted them to relax. Giving careful explanation of procedures beforehand relieved discomfort and distress, disappointment and insecurity for the patient. The findings in this study are also similar to those by Alasad and Ahmad (2005) and Larsson, Sahlsten and Segesten (2011) whereby critical care nurses told the patients what they were going to do without providing any comprehensive explanations about the surrounding environment or social world in all occasions.

In addition, the language barrier contributed to lack of understanding of information and communication in some of the patients who did not understand the local languages in this study. This has been supported by Khathami, Kojan, and Aljumah et al. (2010) who found that their patients were concerned about the language barrier during nursing care delivery as it may lead to miscommunication and compromise the patient-nurse relationship. Given the fact that South Africa is a culturally diverse country (Duma, de Swardt, Khanyile, et al., 2008:84), it is suggested that understanding the cultural aspects of nurse-patient communication barriers can help nurses communicate effectively to all patients (Anoosheh, Zarkhah, Faghihzadeh, et al., 2009).

Ten patients interviewed in this study reported that it was important for nurses to provide explanations before they could carry out any procedures. Although some of these participants received explanations, some of them did not. This could indicate that those nurses who did not provide explanations invaded the patients' privacy and they did not seek consent because they did not provide information about what was going to be done to the patient. It could also be concluded that the nurses did not see the importance of talking, orienting and explaining the procedures to the unconscious, or to someone who were not able to communicate as they were not able to respond. On the other hand, the use of a local language while communicating (that was found to hinder understanding of information) may mean that the nurses do not take their time to know and understand their 'new' patients' background including their cultural values when they report for the new shift.

3C.7.2 "Dealt with like a specimen"

Apart from performing their daily routine activities, patients wanted nurses who could talk, communicate and provide information to them throughout while they were in the ICU. In most cases, it was reported by the patients that provision of information about their condition, their progress and general information was not done. They found nurses engaging more with themselves and the machines than with them as patients. This has been referred to as "dealt with like a specimen" by one of the participants. Some of the study participants said communication with the nurses was good because nurses were talking to them. For example three of them said:

> *"…some (nurses) would talk to me when they to do their job"* (Jacky).

> *"They were talking to me like general things and they told me when they did something like temperature and then they tell me it is good and the blood pressure"* (Tim).

> *"…they talk to me and they smile. I was not able to talk with them but they were talking to me, I could listen. Just to talk to us and smile because it makes you to cheer up also, they must smile to others"* (Lucy).

While some were happy about communication with the nurses, some as shown below were not satisfied with the communication between them and the nurses. Some of them said:

> *"You are dealt with like a specimen. I was just like a specimen, the nurses would communicate between themselves and the equipment, not with me, because they were just busy with the discussion among themselves, engaging with the equipment. There wasn't really any communication"* (Patrick).

> *"No, they (nurses) didn't explain to me about my condition, no one told me. I don't think they know. They just come and turn me after that they go. They didn't tell me anything about my life they just come and look on the screen so they just tell me if I have done something wrong they tell me do this and this"* (James).

> *"…they don't even come and speak to you or ask you stories. You are just err… a number you know. It looks like they don't care, you feel neglected, you feel horrible, I felt run down"* (George).

Supported in literature, effective communication is an essential part of the caring process; however, it could be easily forgotten as was not practiced as it should be in a study by Alasad and Ahmad (2005). Communication is associated with favourable patient-focused outcomes, including satisfaction with care and psychological wellbeing (Nelson, et al., 2010:815). Alasad and Ahmad (2005) found that the level of nurses' interaction and communication with patients was largely determined by the patient's level of responsiveness. Verbal communication between critical care nurses and sedated or unconscious patients was not effectively practiced with unconscious or sedated patients receiving less or no verbal communication and interaction than responding patients.

Inadequate nurse-patient communication existed in this study and has been reported to result in increased levels of stress and anxiety (Alasad & Ahmad, 2005:356). Both verbal and non-verbal communication between the nurse and the patient is important and has a major impact on the patient's emotional stability and perceived care (McCabe, 2004). Communication, as

reported by patient participants in a study by Nelson et al. (2010) is what they waited for every day in the ICU from the ICU team.

As confirmed in a previous study, although technical skills and medical equipment are perceived as necessary lifesaving interventions, nurses should be aware that patients sometimes perceive that increased attention to technical equipment decreases the patients' trust (Hofhuis, et al., 2008:310). As happened in this study, caregivers so strive to master technology that the patient ends up an object of observation, supervision, review and control (Almerud, Alapack, Fridlund, et al., 2008:136). Nevertheless, caring professionals need to balance this state-of-the-art technology with integrated and comprehensive care and harmonise the demands of subjectivity with objective signs (Almerud, et al., 2008:136).

Communication between the nurses and critically ill patients appeared to be a problem from the findings in this study. The majority of the patient participants were not satisfied with communication while in the ICU. They reported that nurses engaged with the machines and among themselves rather than with them as patients. Communication or interpersonal relations is supposed to be the basis of nursing care as opposed to technical care but it was not possible for some nurses as they paid more attention to the machines than on the patients. The reason why nurses could focus more on the technical care than on patient care could be lack of experience handling such sophisticated equipment in the ICU. Due to the shortage of critical care trained and experienced nurses in South African ICUs, it is common to have continuity of care maintained by replacement by newly qualified and agency staff who are not conversant with the equipment used in the ICU. This fact reflects how much time and attention could be focused to the equipment than to the patients. Eventually, the patients end up feeling neglected in the care and in communication process.

Table 3C.5 provides the reader with a summary of the third theme and its related sub-theme. Immediately after the table format, this sub-theme will be discussed in detail.

Table 3C.5 Summary of theme three and its related sub-theme

MAJOR THEME	SUB-THEME
3C.8 TRUST	**3C.8.1** Trust in them

3C.8 TRUST

Trust emerged as a major theme and its related sub-theme "trust in them" will be discussed in the following section.

3C.8.1 Trust in them

Patient participants reported that their trust in the nurses referred to in this section as "trust in them" is important while they are in the ICU. They needed to trust information and the care from the nurses. Some participants trusted that the information regarding their condition was safe in the hands of the nurses. For example, one participant who was HIV positive trusted the nurses more than her family and had this to say:

> *"if you have got HIV like me (whispers), most people don't want this sickness, so that is why I say to you I will only trust the doctors and the nurses"* (Lucy).

> *"I put my hopes to them (nurses) and to their work"* (James).

Despite of this, it was evident that some patients had lost trust in the nurses for some reason. For example, when it came to obtaining information about his illness from the nurses, one of the participants said he did not ask the nurses because he has lost trust in them. He said:

> *"No, I don't even listen to what they say because I have lost trust in them by just how they treat me"* (George).

Another one said:

> *"…nurses were more of administrative. They didn't have much knowledge, they didn't communicate, they had to call someone like another nurse or doctor to come and help. This can make you to start to query the type of care you are receiving"* (Jacky).

Previous studies have shown that having trust and confidence in a health care provider was rated as extremely important by respondents (55.8%) (Heyland, Dodek, Rocker, et al., 2006). On the other hand, similar findings to this study were found by Hofhuis et al. (2008:310) whereby sometimes patients described the nurses' personal approach as negative and this caused patients to be reluctant to ask questions of the nurse and reduced the confidence. In addition, Zyblock (2010) indicates that the patient needs to be able to trust the intentions of the nurse, perhaps more often than any other healthcare professional.

In this study, trust or faith was reported as an important aspect that should exist between the nurses and the patient. While some patients trusted the nurses with their information and their care, some had lost faith in them. The loss of trust could be attributed to the way the nurses treat patients. It is apparent that the nurses' attitude eventually becomes the patients' attitude in that the patients' trust in the nurse can only exist if the nurse treats the patient in a respectful manner. It could also be concluded that some nurses act like clerks as they don't have adequate knowledge and depend on others for help as indicated in the findings. Lack of communication and dependence on others might result in a patient exhibiting lack of faith in the nurses' professionalism.

In **table 3C.6,** the fourth theme and its correlated sub-themes have been summarized. Following this, a detailed explanation of each of these sub-themes will be presented.

Table 3C.6 Summary of the fourth them and its correlated sub-themes

MAJOR THEME	**SUB-THEMES**
3C.9 PRESENCE	**3C.9.1** Nurses' presence **3C.9.2** Family presence **3C.9.3** "You don't want your family to know"

3C.9 PRESENCE

Presence as one of the major themes emerging from the interviews with the patients yielded three sub-themes including: nurses' presence, family presence and "you don't want your family to know". Each of these sub-themes will be discussed in detail as follows:

3C.9.1 Nurses' presence

The presence of a nurse in the patient's room was regarded by some of the patients as important to them. This is because if the nurse is around she or he could assist when the patient need urgent attention or help. The other reason why patients wanted nurses to be at their bedside was because they felt lonely, scared and worried a lot when they were alone especially those who did not share a room with any other patient. They reported that nurses' presence was a sense of security for them and they felt relaxed knowing that there was someone watching over them. Although this was a need, all of them did not receive it as they expected. Some of them said:

> *"I wanted them (nurses) to stay with me. I was in a room alone, I used to think and see bad things it is like the bad things were coming to me"* (Mpo).

> *"If you call them and if you are in agony, they must be there. Mostly, they will not be around; they will only appear when they have to do something otherwise you don't see them. You feel horrible, you feel neglected, you are hopeless"* (George).

> *"…there were times when it could really get so uncomfortable, and they were nowhere to be seen and they would take years to come to you and you would really get so frustrated"* (Jacky).

> *"…they (nurses) could come check on me, talk to me and then they leave and come back again after sometime but me I wanted someone to stay by my side"* (Lilly).

> *"I almost lost my temper the day I got out of ICU because this other nurse left me and she didn't come back for a very long time and I was so uncomfortable and in pain, I needed help"* (Tim).

Establishing presence is a way in which nurses can enhance the nurse-patient relationship, increased levels of trust and safety (Zyblock, 2010:123). Although not practiced all the time in this study, presence in nursing is a holistic approach that involves a sincere connection and sharing of the human experience through active listening, attentiveness, intimacy and therapeutic touch, spiritual exploration, empathy, caring and compassion, and recognition of the patient's psychological, psychosocial, and physiological needs (Karlsson & Forsberg, 2008; Hassel, 2009). The importance of presencing has been shown by Zyblock (2010) in that when a nurse uses physical presence, the patient outcomes include a sense of encouragement, increased motivation and feelings of being heard, and decreased feelings of loneliness and isolation. Similar to what was reported by some of the patients in this study, a study by Hofhuis et al. (2008:308) shows that if the nurses were non-supportive and responded very slowly when patients rang the bell, this caused feelings of helplessness, hurt and powerlessness.

Most of the participants in this study wanted the nurse to be present in the room most of the time for attention and as a source of security. Despite of this, it was reported that the nurses were not always in the patients' room for some time. Patients would be in agony, lonely or worried as there was no one to attend to them immediately when they wanted. Firstly, this could probably be that the nurse was not comfortable sitting by the patient's bedside and preferred to sit at the nurses' station. The second assumption could be the nurse had to assist other nurses with some patient care and could not always stay in the patient's room. The other reason why the nurse could not always be by the patient's bedside could be that the nurse needed some personal time such as time to eat.

Even though it may not be practical for the nurse to always be at the patient's bedside throughout the working shift, it is expected that the nurse should be responsive and not leave the patient alone for a long time. Regular attention might be required as a way of enhancing care and addressing the patients' thoughts of negligence or abandonment.

3C.9.2 Family presence

Family presence was also valued by the majority of the patient participants. They reported that they wanted the family to be present any time for several reasons. One of the reasons was visiting for the company and encouragement as the ICU was regarded as a lonely place. The other reason was the need of the family to be present while offering some direct care. Family presence and participation in decision making was also required by some of the patients in the study.

The three participating hospitals had restricted visiting hours; families could not be present all the day at the patient's bed side as per the patient's wish. Although this is the case, families and friends visited for short periods as allowed by the hospitals and their presence was appreciated by the patients as this was taken to indicate that the family cared about them. Some of them said this about visiting and family presence:

> *"…it will be nice if sometimes a husband or a wife or a son can come in and just be here sometimes alone with the patient outside visiting hours. It is a very lonely experience even if the nurses are around, I know, I have experienced it"* (Cindy).

> *"…family should be allowed more time to stay with me because that place is very lonely and the nurse cannot be there all the time"* (Annie).

> *"I needed to hear a voice of a relative, I couldn't hear, there were just voices of strangers"* (Patrick).

> *"I just want them (family) to stay with me and talk to me or even stay with me at the room. It feels lonely and you start to think about lots of stuff"* (Lilly).
> *"…if you don't see your family you feel sometimes may be they don't care about you"* (Lucy).

> *"…even if they don't do anything practically for me,* just *to cheer me up, to enlighten my emotions"* (Mpo).

"I feel happy because it shows that they are taking care of me. they just talk to me freely and encourage me and I put my hope to what they tell me, it shows that they are taking care of me and if they don't come I will think they are just abandoning me" (James).

"…they (family) came and they could speak to me. I could feel OK to see them and if I don't see them I get stressed" (Tim).

Evidence does suggest that, for patients, flexible visitation decreases anxiety, confusion, agitation, reduces cardiovascular complications, decreases length of ICU stay, makes the patient feel more secure, increases patient satisfaction and increases quality and safety (Bell, 2011). As with participants in this study, patients in a study by Nelson et al. (2010:814) emphasized their awareness of family presence and the comfort and strength they derived from it. Whereas they might appear unconscious, one patient in the study by Nelson et al. (2010) said that they (patients) do hear as she knew each and every person that visited, talked and touched her.

In addition, time with family and friends has also been considered as a top priority elsewhere (Downey, et al., 2009). As valued in this study, research indicates that an open visiting policy may improve the quality of care and satisfaction of patients in the ICU (Whitton & Pittiglio, 2011). These authors continue to say that, although most critical care nurses find that open visiting hours may impede patient care, the benefits to patients and family outweigh any negative impact to the patient.

It is not common for families to take part in direct care of the patients in the participating hospitals. Nevertheless, the researcher sought to determine whether patients obtain comfort when they receive care from their families. When asked if they would wish their families to be involved in direct care, some of the study participants said yes. This to them meant receiving the love from their trusted close families, being close to their families and being in

'safe hands' as the families participated in some activities towards their care. Some of them said:

> *"…it would have been more comfortable because I would know I am in very safe hands just having someone known to me around and participating in some activities other than nurses and doctors. And may be they could help with language problems by telling the staff to speak in English so that we could understand"* (Jacky).

> *"…I would like them (family) to do caring but they didn't take part in caring for me, it was the nurses who did all the things"* (Lilly).

As in this study, family presence and participation in some activities while their patients are critically ill in the ICU have been supported in the literature. In a study by Nelson et al. (2010), families felt they should be allowed to visit patients freely as this could enable them to support patients emotionally, interpret signs that might otherwise be missed and assist in patient care within their capabilities. Similarly, where the patients are usually intubated and cannot speak for themselves especially in the ICU, unrestricted presence of a support person can improve communication, facilitate a better understanding of the patient and advance patient- and family-centred care (Bell, 2011:53).

A number of patients wanted their families to be present and act on their behalf with decision making especially when they were critically ill and unable to talk for themselves. They mentioned that they would like their family members with some preferring very close family members to be involved in decision making process. Three of them said:

> *"I wouldn't mind my family being there for me because they know me better than the doctors, nurses or my friends"* (Duke).

> *"…he (husband) understands me better than anyone and he is in a position to refuse or accept anything told to him because he knows what is best for me"* (Jacky).

> *"I think it would be OK if they can involve them but it must be my very close family like my mother or sister because I don't trust the others so much"* (Lucy).

Some of them wanted the same but the problem is that most people live in the urban areas where these hospitals are situated while they work and their families stay far away from these hospitals. In such cases, they reported that the doctor would always be the best person to act on their behalf. For example, one of them said she would be happy if her sister could participate in decision making process but due to the fact that her sister stays far away, her only choice as to who will make the decisions on her behalf would be the doctor.

> *"I stay far away from my sister, if something has to be done urgently for me, so who is going to decide? I can say the doctor, I prefer a doctor"* (Mpo).

Ideally, decision making in the ICU is based on a partnership between the patient, his or her family, and the multi professional team (Davidson, Powers & Hedayat, et al., 2007:608). Similar to the state in which the patients in this study were at the beginning of their admission to the ICU, Bell (2007) indicates that critically ill patients are commonly unable to think and participate in decisions as they may be unconscious, intubated, sedated and ventilated. As agreed by most patients in this study, much of the discussion about what is happening to them and decisions about treatment therefore, take place between the patient's family and the critical care physicians and nurses (Efstathiou & Clifford, 2011).

In addition, the preference of patients having very close family members to participate in decision making in this study has been supported elsewhere. The findings by Mirzaei, Milanifar and Asghar (2011) who investigated ICU patients' perspectives of who makes better decisions indicated that people who are usually consulted for decisions concerning patient treatment are significantly different from the patients' preferred substitute decision makers. The authors suggested that patients should be allowed to choose their substitute decision maker while conscious.

The majority of the patients interviewed in this study wanted their families to be around any time they wanted. They reported that ICU is a lonely experience and they need their families to be around for company and for encouragement while they are sick as it made them feel better and relaxed. The need for family presence was also for participation in different aspects of care and in decision making process. Some patients mentioned that their families knew them better than ICU staff and were in a position to advocate for them when there was a need. While this was their preference, it may not be possible for the families to have access to the ICU at any time they or their patients wish. This is because the three participating hospitals had restricted ICU visiting times ranging from 12 hours a day, three hours a day and two hours a day. In order for the families to be available for the sake of these patients, it would mean having flexible visiting times and open access endorsed by the hospital management.

3C.9.3 "You don't want your family to know"

While family presence was regarded as beneficial by the majority of the participants, some participants, mainly the elderly, did not mind if their family would not visit frequently, participate in direct care or in the decision making process. They were more comfortable with the nurses doing all that needed to be done to them rather than the family because they did not want the family to know about some things they held private. One of the participants who was HIV positive, did not want the family or friends to know any information regarding her condition. She was not comfortable with the family or friends visiting as she believed that most of the time they do not come to genuinely visit but rather to find out about her life and illness. She said:

> *"I am OK with nurses, when I have these nurses it is like I am with my family and the nurses are better than family. Family sometimes they don't really come to see you genuinely. You can't trust the family. And I think God is most important and the doctors and the nurses because sometimes there is (lowers her voice and moves closer to me so that I can hear) other sickness that you have and you don't want your family to know and if they know, they are going to spread you"* (Lucy).

Another one did not want the family to participate in whatever task and she preferred the nurse as the nurse would know her job better compared to the family. She said:

> *"…it won't be all right, I am not happy about that because the nurses they know their jobs and they see every dirt that you are carrying with you so it is better if the nurses can do all the care, I would still want the nurse"* (Niki).

As mentioned in the literature (Kotak & Lawson, 2008; Zyblock, 2010), sharing information with others is normally done only with the patient's express consent. However, if a patient lacks capacity as would be the case with ICU patients, information may need to be routinely shared with relatives, friends or carers to enable an assessment of the patient's best interests. Although this is the case, information should only be disclosed in the patient's best interests, and then only as much information as is needed to support their care, taking great care to avoid breaching confidentiality or creating difficulties for the patient. In addition, information obtained from the elderly patients in this study reflect the findings by Downey et al. (2009) who found that older respondents place less emphasis than younger respondents on the social aspects (time with family and friends).

A few participants interviewed in this study expressed their concern about the presence of the family. They mentioned that they were not comfortable with their family/friends presence as in most cases, they genuinely do not come to visit or assist in any way but they come wanting information that may be regarded as 'private' to the patient. This portrays the extent to which the patients have trust in the nurses and their need for the nurses to take full control of their lives while they are in the ICU. They have entrusted their bodies and their information to the hands of the nurses, their faith in the families and friends cannot be compared to the trust in the nurses as nurses know what and how to do.

In **table 3C.7,** religion and spirituality as a major theme, including its three connected sub-themes, has been summarized. For clarity, each of these sub-themes will be discussed after the table presentation.

Table 3C.7 Summary of theme five and its sub-themes

MAJOR THEME	SUB-THEMES
3C.10 RELIGION AND SPIRITUALITY	**3C.10.1** Personal prayers **3C.10.2** Prayers from nurses **3C.10.3** Prayers from spiritual leaders

3C.10 RELIGION AND SPIRITUALITY

Religion and spirituality emerged as one of the major themes from the interviews conducted with patient participants. Three related sub-themes including "personal prayers", "prayers from nurses" and "prayers from religious leaders" will be discussed in the following section.

3C.10.1 Personal prayers

The majority of the patients mentioned that they used to pray while in the ICU asking God to heal them and let them recover. Some said:

> *"…if I pray he will answer and heal me and I always pray in my bed and I cry to him all the time because He is the source of power"* (Jacky).

> *"I used to pray and pray and pray because I believe in God that He can heal me and get me out of the hospital and I have hope and faith that He will do that"* (Lilly).

Even though some traditional African patients believed in ancestors prior to the time of their illness, they reported that all that was important to them while in the ICU was God and prayers. They had hope and trusted that God would heal them. Some of them said:

> *"I believe in my ancestors, but the problem is I didn't put my ancestors in front. I put God first. The only one I was crying to, was God"* (Niki).

> *"…we don't believe in traditions, we believe in God we are not people who believe in those sangomas and inyangas, no, we just pray the only thing that is going to help is God"* (Lucy).

Some participants believed that God had healed them. They prayed and had hope while they were sick. They mentioned that before their illness, they did not regard religion as a serious issue but their illness and recovery acted as a motivation to go to church. They said:

> *"I said to God you heal me and I believed in Him and he did heal me. If there was no God and if I did not believe and have hope in Him, I would not be alive now and as from now, I will go to church every day*" (James).

> *"I never used to go to church. I used to listen to bible on TV but now I will start going to church because God has made me new (mm) he has saved my life. I do believe and have hope that my strength and complete healing will be restored"* (Rubby).

As described by Papadimos, Maldonado and Tripathi et al. (2011:141), spirituality deals with beliefs, faith, hope, attitude and the meaning and purpose of life through reflection and appreciation outside of a particular belief system. In religious coping, patients use their belief systems to understand their situation and deal with their stress through prayer, meditation and studies of their religion. In this study, patients incorporated both spirituality and religion and valued them while they were critically ill in the ICU.

In this study, majority of the patients believed in prayers as a means of healing. They had hope that, when they pray, their prayers would be answered and they would recover. They sought comfort and peace from God through prayers while they were in the ICU. It is apparent that their recovery had strengthened their faith in God. To some it was a motivation to continue praying and attending religious services after their discharge.

3C.10.2 Prayers from nurses

Out of all participants, only one of them reported that she received spiritual support from the nurses. This, as mentioned by this participant, gave her emotional stability. She said:

"I got a lot of emotional support and prayers even from sisters (nurses). One sister (nurse) took her time and talk to me about God so it gave me emotional stability" (Annie).

When asked if they received any spiritual support from the nurses, most participants said that this was not available from the nurses. They either received this form of support from the family, spiritual leaders or as a personal act. One of them said:

"Nurses don't pray for you, I used to pray for myself always in the bed" (Zodwa).

Recognition of the patient's spiritual needs is associated with greater satisfaction (Gries, Curtis, Wall, et al., 2008) and should be considered by the health care team (Davidson, et al., 2007:612). Lack of ICU team participation in spiritual support in this study may be associated to a statement by Ott (2010) who said that those who care for dying patients in critical care are often confronted with their patient's spiritual concerns but this spiritual issue may make them uncomfortable as they feel unprepared to address it.

Despite praying for themselves, patients in this study also needed support from other people such as the nurses. With only one nurse providing spiritual care, the findings revealed that it is rare for the nurses to offer spiritual support. This may not mean that all the nurses were not religious or did not believe in a supreme God but it would probably be due to the notion that it is not their 'job' or because they are not prepared to do so for the patients.

3C.10.3 Prayers from religious leaders

Some of the patients in this study received spiritual support from known religious leaders to them whereas some of them received the same support from unknown/volunteer religious leaders to them. Participants had different views regarding the spiritual support offered by either known or unknown religious leader to them. While all the leaders did prayers that gave hope and encouragement to the patients, the majority mentioned that they wanted prayers from religious leaders known to them as opposed to unknown religious leaders. Those who valued prayers from known leaders said:

"…if it is the pastor from my church or my own choice, then it is fine" (Jacky).

"She (mother) brought the father from the church. Spiritually I was mended and physically the courage he imparted in me gave me hopes and made me believe that I was going to get well and it was good that he came" (George).

While others did not mind having any religious leader pray to them, some did not want such a service for different reasons as follows:

"…it is not right because we all don't believe in one thing and the prayers depend on one believing where the pastor or person praying is coming from" (Jacky).

"You don't trust anyone to do things for you because you don't know their intentions. I would rather do personal prayers than have someone I don't know. I may not believe in what he says. You know prayer is about faith and believing and when you pray you must believe so that it can happen. Sometime you feel you need empowerment from the father or a bishop but, my darling, now days they only need money for anything and we haven't got money" (Cindy).

"We don't believe the same all of us and I may not believe in whatever other strange person pray to me about. It will be better for me to pray for myself if my own bishop cannot come" (Duke).

"I am not comfortable if someone I don't know come and pray for me, I just can't believe in any prayer from anyone" (Mpo).

Some of the study participants who were comfortable with any religious leader offering spiritual support said:

"I saw a white man who came here to pray for us and it is good if they can come because we need them for encouragement, for comfort and peace just to know that there is God who can heal and protect us" (James).

"I was admitted here sometime back and I used to see groups of people coming to pray but I haven't seen any this time round. I think it was good for them to come because many people are religious and if we receive such services we get that hope" (Annie).

Similar to the findings in this study, participants in a study by Nelson et al. (2010) mentioned that pastoral care should be available for patients or families who want it and it should not be forced upon anybody. A need to understand cultural differences exists and such a need encompasses consideration of factors such as ethnicity, religion or spirituality (Carey & Cosgrove, 2006:265). It is important for a nurse to be aware of the cultures and backgrounds of their patients and to show respect for cultural differences (Duma, et al., 2008:85). ICU team therefore, must understand and be sensitive to the effect of religion and spirituality upon their patients' (and families') decisions in the ICU (Papadimos, et al., 2012).

The findings from this study revealed that while some patients expressed the need to have religious leader known to them to offer spiritual care, some valued any religious leader available to them. This means that if possible, the hospital management should seek and respect the patients' preferences before allowing any religious leader to access and offer spiritual support to the patients in the ICU. This will act as a way to ensure respect towards the patient's spirituality, religious beliefs and their choices.

3C.11 CONCLUSION OF THE FINDINGS

Even though they were not receiving end of life care, the results obtained from the critically ill patients' experiences of comfort care in the ICU in these interviews provide significant understanding into the patients' thoughts regarding comfort care in the ICU. Their narratives provide important information that could contribute in guideline development which will direct intensive care nurses caring for the patients at end-of-life.

One of the major finding from the interviews in this study is the patients' desire to be cared for by someone who would feel and understand what they are going through while admitted in the ICU. Although compassion including psychological care or reassurance was not valued all the time by the nurses, it meant a lot to the patients. Nurses' compassion and reassurance meant that the nurses cared and contributed to their psychological satisfaction and decreased anxiety.

While the majority of the patients reported that their personal hygiene was maintained, patients also wanted their dignity to be always upheld by the nurses. In addition, inadequate pain management appeared to be the most common problem for the patients interviewed in this study and this reflects how uncomfortable the majority of the patients were. To add to their discomfort, it was reported that the ICU was too noisy and this contributed to disturbances in sleep and relaxation.

Another significant finding that emerged from the patient participants' interviews was communication. The majority of the patient participants were not happy with communication between them and the nurses. Even though they were not able to respond or talk, most of them could hear but seemingly their non-responsiveness might have let to decreased amount of communication from the nurses. It felt like intrusion of privacy when the nurses went ahead with the interventions (as it happened to some patients) without explaining the procedure or informing the patient about what was about to be done beforehand. It was also evident that patients desired to receive information in a language they could understand and to be oriented not only about interventions but also about what was happening in their surroundings.

In addition, though technology contributes to caring, it was found that some nurses concentrated much on the machines and equipment with less attention directed to the patient. When lack of attention and communication occurred, patients felt neglected and they appeared just like an object of care and not human beings. It is thus thought that communication with sedated or unconscious patients in ICUs should not be viewed as only an

interactive process. Rather, it should be perceived as a means of providing the information and support that such patients need hence reduced amount of stress.

Trusting the nurses appeared as another important theme from the patient participant interviews. While some patients trusted the nurses with their personal information and their care, some had lost faith in them. The loss of trust in the nurses was mainly due to the way nurses treated the patients. Lack of respect and unprofessional behaviour towards the patient contributed to a loss of trust in the caring nurse. In addition, as mentioned by some of the participants, the nurses' lack of knowledge and inability to communicate and share information to the patient were also regarded as sources of mistrust between the nurse and the patient.

Of importance to the patient participants also was presence. The presence of a nurse at the patient's bedside was valued by all the study participants as a source of relief, safety and security. Even though it may not be practical for the nurse to be at the patient's bedside throughout, the nurse should make an effort to attend and respond to the patient's needs on a regular basis. This will serve to alleviate worries and anxieties that were found to be common in study participants in this study.

The presence of family though not valued by two of the patients was considered to be of importance by most of the participants. Those who did not want family to be around believed they were comfortable in the hands of the healthcare providers. They perceived the presence of family and friends as a threat to their lives because they did not want families to know about some things going on in their lives.

Those who mentioned that the presence of the family is important wanted more time with them outside visiting hours as they did not only get encouragement from them but it also made them feel safe. While some wished the family could participate in their care, some wanted the family to be involved in the decision making process as this was the only way their preferences could be known to the health care personnel especially during the time they were critically ill and not able to communicate.

Finally, religion and spirituality which arose as one of the major findings in this study was valued by all the patients. In most cases, patients prayed for themselves in their beds. Prayers gave them solace, hope for recovery and drew them closer to God. While most of them received spiritual support from the family and friends, this was seldom offered by the nurses or ICU team except in one occasion where a nurse prayed with one of the patients.

On the other hand, patients also valued spiritual support from religious leaders. Whereas some of them wanted such a support only from the religious leaders known to them, some did not mind having any religious leader coming to pray for them. Bearing in mind that patients came from culturally diverse population with different religious backgrounds, those who did not want prayers from unknown people believed that prayer is about believing what the bishop/father/priest/pastor says and where he comes from. This division about who should offer the spiritual care showed that ICU team should bear in mind about the patients' religious backgrounds and respect their preferences if they have to organize or allow religious leaders to offer such a care the ICU.

Generally, the findings in this study revealed a mixture of experiences and thoughts from the patients. The type of nursing care received by the patients reflected how comfortable they were in the ICU. The majority of the patients were not happy about the nursing care they received while admitted in the selected ICUs. Therefore, it could be concluded that comfort in care offered by nurses to ICU patients in these study settings is not adequate.

3C.12 SUMMARY

This chapter presented methodology and the findings from the interviews that were conducted with the patients. Biographic information of the participants, discussion of major themes and sub-themes arising from the patient interviews including the conclusion of the findings and a summary has been provided.

The following chapter presents the methodology and the findings of intensive care nurses' experiences of end-of-life care.

CHAPTER 3D
INTENSIVE CARE NURSES' EXPERIENCES OF END-OF-LIFE CARE

3D.1 INTRODUCTION

In the previous chapter, research design and methods including the findings on critically ill patients' experiences of comfort care were presented. This chapter relates to step 4 of stage I of the study and it presents research design and methods including the findings and discussion of the major themes that arose with regard to intensive care nurses' experiences of end-of-life (EOL) care in the ICU. The participants' profile has also been presented followed by a detailed discussion of the results, a brief conclusion of the results and a summary. **Figure 3D.1** outlines the summary of the process for conducting this chapter.

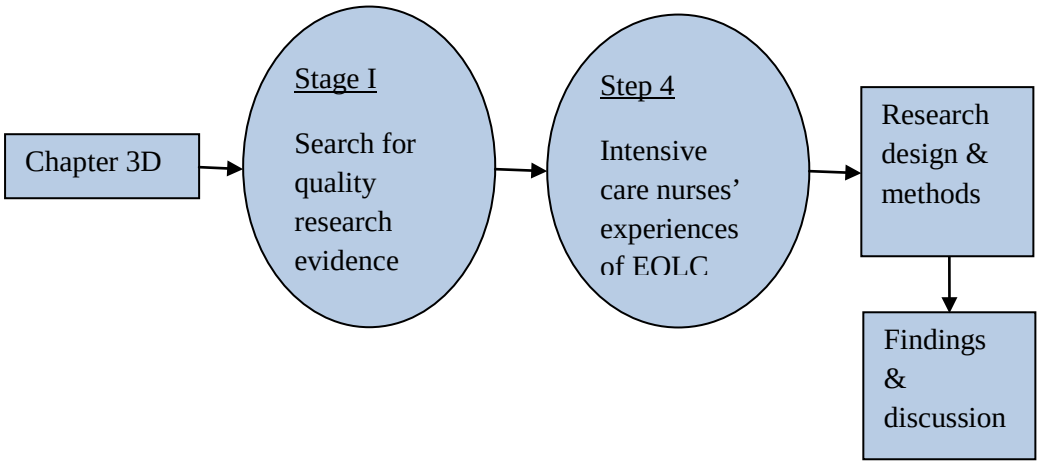


Figure 3D.1 A summary of the presentation of chapter 3D

3D.2 RESEARCH DESIGN

A descriptive, qualitative design was used to describe the experiences of intensive care nurses on EOL care.

3D.3 RESEARCH METHOD

3D.3.1 Target population

Burns and Grove (2007) describe the target population as the entire set of individuals who meet the sampling criteria. The target population for nurse participants included all registered nurses who were working in either multidisciplinary, trauma or cardiothoracic ICUs from the three hospitals between September, 2012 and November, 2012.

3D.3.2 Sample and sampling method

A sample is a small portion of the total set of persons from which a representative selection is made (De Vos, et al., 2011). As recommended by Kvale (2009), a range of six to ten subjects is suitable for a focus group discussion as this allows everyone to participate while still eliciting a range of responses. The greatest amount of new information has been reported to come in the first two focus groups with considerable repetition after that, but as a rule of thumb, four focus groups have been suggested with re-evaluation after the third (De vos, et al., 2011). In this study, group discussions were conducted until there was no diverse range of responses to the topic of discussion. In this case, three focus group discussions were conducted. The first focus group comprised of nine (n=9) nurses whereas the second group included seven (n=7) nurses with eight (n=8) nurses participating in the third group.

A non-probability purposive sampling method was used to select intensive care nurses so as to elicit their experiences of EOL care in the ICU. In focus group research, the strategy is to use purposeful sampling whereby the researcher selects participants based on the purpose of the study (Krueger & Casey, 2000:204; De vos, et al., 2011:365).

Inclusion criteria for the nurses:

- Nurses with more than six months of practice experience in the ICU to ensure that they have been involved in the care of a patient at EOL
- Working in the adult ICUs at the selected study sites
- Provided written consent to participate has been obtained

3D.3.3 Data collection procedure

Following permission from the relevant authorities to conduct research, the researcher purposively selected nurse participants for each of the focus group discussions. With assistance from the unit mangers and clinical assistants, initial contact and recruitment of study participants was done following documented strategies (Krueger & Casey, 2000; De vos, et al., 2011).

Once focus group discussion dates, times and locations had been set, before each focus group discussion, the researcher made contact with the participants. Participants were invited and made aware of the study, what needed to be covered and the importance of the study. In each focus group discussion, over recruiting by two was ensured to cover for non-shows. Each of the participants was asked to provide their telephone contact details as this allowed the researcher to do a follow up on attendance to the focus group discussion.

Days before each of the focus group discussions, participants who agreed to be available for the focus group discussions were sent an information letter (refer to **appendix U**) in sealed envelopes providing details about the focus group discussion, location, topic of discussion and what will be offered as incentives. On the day before the focus group discussion, the potential participants were contacted telephonically to remind them of the focus group discussion and to confirm their attendance.

On the day of focus group discussion, the facilitator/researcher and assistant facilitator (whose role was to take field notes, record actual conversation and her observations of group

behaviour) arrived at the venue earlier before it was time to start the discussion. The chairs were arranged so that all group members could see each other in order to facilitate good communication. Refreshments were set up on a table to the side of the room ready for participants so as to promote conversation and communication within the group (De Vos, et al., 2011). As the participants arrived they were greeted and introduction to one another was done as a small talk so as to create a comfortable and a friendly environment.

As soon as a sufficient number of participants were present, the participants were asked to sign two consent forms; one for inclusion in the study and the other one for the use of a tape recorder (refer to **appendices V** and **W** respectively). The need for a tape recorder was clarified to the participants including the fact that the information would be confidential and that all the tapes will be kept in a locked cupboard with data being under password protected computer. To begin the focus group discussion, the researcher welcomed everybody, provided an overview of the topic, general discussion guidelines and the rules to be adhered to during the focus group discussion. After which, following an introductory comment, the first question designed to get all participants saying something was posed as stated below.

> *"Experience in caring for critically ill patients make you 'experts' in intensive care, what comes to your mind when you think about caring for a patient at end-of-life in the ICU?"*

Focus group guide (refer to **appendix X**) was used during the focus group discussions. A five second pause was allowed after each participant had completed making his her idea as this helped in drawing additional information from group participants (Krueger & Casey, 2000:110). Probes were used during the focus group discussion to deepen the response to a question; increase richness of the data obtained or give clues to the participant about the level of the desired response (De Vos, Strydom & Fouche, et al., 2005).

Different focus group discussions were conducted until no new information, which indicates a point of saturation was attained (Kvale, 2009). Saturation was reached after the third focus group discussion hence data collection was terminated. `

3D.3.4 Data analysis

As stated by Polit and Beck (2012), verbatim transcription of the tapes is a critical step in preparing for data analysis. In this stage, the researchers need to ensure that transcriptions are accurate and that they validly reflect the interview experience. Since data collection and data analysis occur simultaneously in qualitative studies (De Vos, et al, 2011), verbatim transcription was done immediately following each meeting in preparation for data analysis. Field notes were placed in their respective places in the transcripts. Pauses were written in brackets as (pause). Similarly, recorded voices such as sighs or sharp reactions were written in brackets within the context of the statement. After completing each transcript, the researcher checked for accuracy by reading and listening to the tape recorded interview and making necessary corrections (Kvale, 2009).

Once verbatim transcription was completed, data were analysed using the long-table approach (Krueger & Casey, 2000). The long table approach allows one to identify themes and categorize results. Following this approach, the whole process of how analysis was conducted by the researcher is described below.

The researcher preferred using the wall at home instead of the table to spread out the work and to prevent disturbance until analysis was done. In each group, two copies of transcripts were printed. One copy from each group was for cutting apart (the working transcript) while the other copy was used for reference in case the researcher wanted to know where the cut quote came from originally or wanted to examine the context of a particular discussion. The intact transcripts were kept in the file. For easy identification of which group the quotes came from after cutting them into several pieces, the first group discussion transcripts were printed on a green colour paper whereas a yellow colour paper was used for the second group and a pink colour paper for the third group.

The working transcripts were arranged from the first to the third group as this arrangement helped in recognizing the changes that occurred from one group of participants to another. Before cutting began, a repeat quick reading of all transcripts was done. This was mainly to remind the researcher of the whole scope and to refresh the memory of what was said in the

groups, where information is located, what information is missing and what information occurs in abundance. A manila sheet of paper was then stuck on the wall, starting from one corner of the room. All the questions that were asked during the meeting and were to be analysed were then written on top of each Manila paper. Each paper was then divided into three sections, to place comments from the three different groups.

Cutting and categorising began by reading each quote on the transcripts to see if the participants answered the question asked. The comments that were of importance to the topic were then cut and taped to the Manila sheet of paper under the appropriate question section or location. Like quotes were grouped together by moving the quotes around in order to form categories. Constant comparison was done for all the quotes to determine the similarity or difference from the quotes.

It was discovered by the researcher that not everything necessarily fits into the categories because some aspects discussed by the participants were of minimal importance to the study with some going off the topic. In such instances, such information was not thrown but instead, it was saved and later rechecked for unused quotes. In such instances, categories were rearranged or new categories were created by checking if these unused quotes fitted the new categories. Rearrangement was done until the researcher was satisfied that all quotes that talked about similar things were together. Two postgraduate student colleagues at a PhD level from the nursing education department were asked to review and comment on the categories in order to enhance the analysis. Both of them have previously conducted qualitative research and analysis and are lecturers and research supervisors from two different universities hence familiar with qualitative analysis. Their suggestions assisted in further rearranging the quotes that fitted in certain categories and had not been realized by the researcher.

Once this was done, the researcher wrote a descriptive summary of what each group said in response to the question so as to allow comparison and contrasting. During this stage, emphasis was put on comments that were specific; those that provided detail, comments which participants showed intensity and enthusiasm, the comment’s extensiveness and frequency were also noted.

Following the descriptive summary for each of the questions, the researcher developed themes by looking for things that came up repeatedly across the questions as this allowed structuring the written report around these rather than around the questions. Before conclusion of the analysis, the researcher took a break away from the data as a way of refocusing the attention to the big picture and reflecting on the findings and how to frame the information so it best conveys what participants shared.

Finally, summaries written earlier under descriptive summary were written to describe what was said about the emerging themes. This was followed by selecting quotes which act as evidence from the categories that illustrated what was said. Once this level of analysis was completed, the researcher's interpretations, meanings and recommendations of the findings were presented. For auditing purposes, refer to **appendix Y** for a portion of an analyzed transcript.

3D.3.5 Pilot study

As stated by De Vos et al. (2011), pilot testing a focus group is difficult, and although pilot testing is a basic rule of research, it presents special problems with focus groups. The reason behind this is that the questions in focus group interviews are hard to separate from the environment of the focus group. Therefore, the true pilot test is the first focus group with the participants. In this regard, the first group discussion in this step of study acted as a pilot study. This first group provided the researcher with better techniques of handling the subsequent group discussions (including time management, clear recordings and managing group diversity/behaviours). The questions that had been set were not altered as there were no difficulties encountered during the interview process.

3D.4 THE PROFILE OF THE NURSE PARTICIPANTS

Table 3D.1 below shows the summary of the profile of the nurse participants in this stage of the study. Three group discussions were conducted with a total of 24 nurses working in the adult ICUs at the selected study sites. The majority were female (n=22; 91.67%) participants. Most of the participants fell between 51-59 years old (n=9; 37.50%) followed by those within

31-40 years old (n=7; 29.17%) and then those between 41-50 years old (n=6; 25.00%) with a few of them being within 60-69 years old (n=2; 8.33%).

In terms of years of experience in the ICU, the majority of the study participants (n=9; 37.50%) had a range of 6-10 years followed closely by those with 11-15 years (n=8; 33.33%) and then those with 16-20 years (n=4; 16.67%). The most experienced (n=2; 8.33%) had more than 21 years of ICU experience whereas the least experienced (n=1; 4.17%) had 2-5 years of ICU experience. In addition, all study participants had acquired a qualification in critical care nursing. Most of them (n=14; 58.33%) had post basic diploma in critical care nursing. Eight (33.33%) of them had postgraduate diploma in critical care nursing whereas two (8.33%) of them had a masters degree in critical care nursing.

Table 3D.1 The profile of nurse participants in the focus group discussion (n=24)

Demographic information		**F (%)**
Gender	Male	2 (8.33)
	Female	22 (91.67)
Age group in years	31-40	7 (29.17)
	41-50	6 (25.00)
	51-59	9 (37.50)
	60-69	2 (8.33)
Years of ICU experience	2-5	1 (4.17)
	6-10	9 (37.50)
	11-15	8 (33.33)
	16-20	4 (16.67)
	>21	2 (8.33)
Level of training	Post basic diploma in critical care nursing	14 (58.33)
	Postgraduate diploma in critical care nursing	8 (33.33)
	Masters degree in critical care nursing	2 (8.33)

3D.5 FINDINGS AND DISCUSSION

A summary of the five major themes that emerged in this step of the study and its sub-themes are presented in **table 3D.2**. These major themes included: “difficulties we get”, “discussion and decision making”, “support for patients”, “support for families” and “support for nurses". Following which, the findings will be described and then illustrated by means of extracts from the discussions. Immediately after this, reference of relevant literature will be provided.

Sub themes identified will be used to further help clarify the major themes. For clarity, a summary of each theme and its sub-themes will be presented in a table format.

Table 3D.2 Themes and sub-themes emerging from nurse participants

MAJOR THEMES	SUB-THEMES
3D.6 "DIFFICULTIES WE GET"	**3D.6.1** Psychological and emotional stress **3D.6.2** "Tell or not to tell" **3D.6.3** "She wants to hear what she wants to hear" **3D.6.4** "I don't want this to happen to me" **3D.6.5** Little hope **3D.6.6** "Who to call"
3D.7 DISCUSSION AND DECISION MAKING	**3D.7.1** "Told not involved" **3D.7.2** "Being on the same page"
3D.8 SUPPORT FOR PATIENTS	**3D.8.1** Spiritual support **3D.8.2** "Until nature takes its course" **3D.8.3** Presence **3D.8.4** "Noise is like normal" **3D.8.5** Patient's advocacy **3D.8.6** Private room
3D.9 SUPPORT FOR FAMILIES	**3D.9.1** Support person **3D.9.2** Respect **3D.9.3** Open access **3D.9.4** "Staying with them" **3D.9.5** Gradual preparation **3D.9.6** Hospitality
3D.10 SUPPORT FOR NURSES	**3D.10.1** "Just to talk with somebody" **3D.10.2** Team work **3D.10.3** Training **3D.10.4** Shift changes **3D.10.5** Time to adjust

3D.6 "DIFFICULTIES WE GET"

"Difficulties we get" emerged as one of the major themes from the focus group discussions with intensive care nurses. It was reported by the nurses that caring for patients at EOL is a challenging and a difficult process. Several sub-themes under this major theme came up as presented in **table 3D.3** and discussed in the following section.

Table 3D.3 Summary of theme one and its related sub-themes

MAJOR THEME	SUB-THEMES
3D.6 "DIFFICULTIES WE GET"	**3D.6.1** Psychological and emotional stress **3D.6.2 "**Tell or not to tell" **3D.6.3** "She wants to hear what she wants to hear" **3D.6.4** "I don't want this to happen to me" **3D.6.5** Little hope **3D.6.6** "Who to call"

3D.6.1 Psychological and emotional stress

When asked about their experiences of caring for patients not for escalation of treatment, all of the study participants reported that it is challenging both psychologically and emotionally. The sources of these challenges were sometimes associated with the age of the patient, the type of illness and the bond that has developed between the nurse and the patient. It was mentioned that caring for such patients is a painful, touching, traumatic, heartbreaking, depressing, draining, disturbing and stressful experience. For example, some of the participants said:

> "*The difficult part of it is the psychological disturbance we have to go through. T*he type of illness and age of the patient is got effect (Nurse 9).

> "*It is really touching* especially the young aged ones. *You feel you are part of what is happening to the patient and for the family as well"* (Nurse 20).

> "*The most stressing and challenging thing is when you have built relationship with the patient. Then you have to go through looking at hemodynamics, seeing the patient going down until the end. That is the most draining part, you are with the family, you see bradycardia, you see everything. Unlike the patient who just come in with MVA or PVA and things happen quickly and then it is over."* (Nurse 14).

It is suggested that end of life care is a major source of stress for ICU physicians and nurses (Pattison, 2011) since in most units, the responsibility from clinical decisions to relations with the family falls exclusively on their shoulders (Gristina, Gaudio & Mazzon, et al., 2011). In addition, Hov, Hedelin and Athlin (2007) found out that being close to the suffering of

patients and relatives caused the nurses to suffer too and this led to exhaustion for some nurses. It has also been reported that nurses get emotionally involved when caring for dying patients especially the young patients or when they have looked after the patient over time and have got to know the family and have built up a relationship (Badger 2005a; McMillen, 2008; Fridh, Forsberg & Bergbom, 2009a; Vouzavali, Papathanassoglou & Karanikola, et al., 2011).

All participants in the focus groups reported that they often experience distress during the caring and dying process of a patient at end of life. This form of distress could be associated with natural feelings of empathy as a human being as nurses put themselves in the patients' and families' positions. In some instances, it could also be that the disturbances (psychological and emotional) in the nurses could be related to the previous experiences of lose in real life.

It was also apparent that nurses felt traumatised caring for certain types of patients at end of life. For example, any stated that it was heartbreaking to provide end of life care for a younger patient as compared to an older patient. This may well be related to the thought that the young patients still needed to achieve many things in life but they were not going to have a chance to do so. On the other hand, the longer the patient remains in the unit, the stronger the bond and the relationship formed with the patient and the family by the nurses. The care and death of such patients inflicted more pain on the nurses as it could have been hard to detach, let it go and accept the circumstance.

3D.6.2 "Tell or not to tell"

Most of the study participants reported that disclosing information to the family is one of the challenging issues they face while caring for patients at EOL. They reported that sometimes they reach a point where they are not sure whether to tell or not to tell. This is because telling could either put them in a 'tight' corner as families could use their words to blame, lead to miscommunication or confusion among family members or could be beyond their scope of practice. In such instances, nurses disclosed minimally to their level. When the family

required more information, nurses tended to refer them to the doctor. Concerning this, some of the participants said:

> *"You know they will come and then you are in a tight corner, you don't know what to tell them but you promise them to call the doctor* (Nurse 19)".

> *"Others want you to make promises. They want to put you at the corner, they will say the sister (nurse) said this and this, she said the patient will be OK, why is he dying? They want to find something to blame you, so I don't talk to them a lot. I refer them to the doctor to avoid confusion and misinformation"* (Nurse 2).

> *"…you tell them what you know. Usually you disclose minimally up to the nursing point. If they need deeper facts then you refer them to the doctor. I must not be too committed* (Nurse 17).

Communication is a cornerstone and a fundamental skill in nursing practice (Malloy, Virani, Kelly, et al., 2010). Despite availability of communication tools that can offer nurses strategies for approaching difficult conversations and knowing what to say (Shannon, Long-Sutehall & Coombs, 2011), nurses still encounter problems in dealing with conversations at end of life. In the field of palliative care, the role of medicine in ''breaking bad news'' has been emphasized with much less emphasis on the role of nursing in supporting patients and families after bad news has been received and throughout the course of illness and until the time of death (Malloy, et al., 2010).

Just as nurses did in this study, nurses in a study by Calvin, Lindy and Clingon (2009) expressed reluctance in providing information to the families. In turn, they referred them to the doctor because they felt as nurses they would not answer some of the questions asked by the family. In addition, nurses in a study by Badger (2005a) mentioned that one has to know where to draw the line when confronting the families. This could be associated with the thought that when the families hear various and divergent information and opinions, both formal and informal regarding the patient's condition from numerous health care

professionals, it could create further confusion and obstacles to providing effective end of life care (Beckstrand & Kirchhoff, 2005).

Communicating to and with families who have patients at end of life was a challenge to all participants in this study. This can be attributed to the boundaries in which the nurses have to disclose information to the families or patients based on their scope of practice. On the other hand, it could mean that nurses are not well prepared on how to deliver information and what to, or how to respond to the families' concerns in such emotionally charged situations. Moreover, it could be that nurses are afraid that what they say could contradict with the doctor's explanations or could be used by families to blame them hence they retreat to silence and often refer families to the doctor for further details.

3D.6.3 "She wants to hear what she wants to hear"

The other challenge faced by intensive care nurses caring for patients at EOL was dealing with families in denial and want to hear what they want to hear. Some regarded such families as trouble makers whereas some stated that it may not be the case as families respond differently to such bad news and this could be due to their emotional disturbances. Some of them said:

> *"…some of them as I have seen respond with anger and anxiety so we might interpret these family members as trouble makers, but personally I have found that this is due to their emotional state"* (Nurse 13).

> *"…when you talk to the family you will hear them, and say this one wants me to commit myself, she wants to hear what she wants to hear. You need to be alert, don't do something that will put you in problems"* (Nurse 22).

> *"…difficulties we get is the denial from the families who will tell you no, what you are telling us is not right, our father is going to wake up and he is going to walk out of this ICU. When the inevitable happens, what do you say to that person? But as a nurse you know we have got stages of grieving, they will deny, cry, shout, blame and*

eventually they will accept. So you take it as one of those steps and then you just have to deal with it as it comes" (Nurse 17).

The behaviour of families wanting to hear what they want to hear has been reported by Calvin et al. (2009). Families may begin grieving when the decision is communicated and responses that health care workers may find challenging include anger and hostility, bargaining, denial or withdrawal (Downey, Engelberg, Shannon, et al., 2006; Crump, Schaffer & Schulte, 2010; Hurley, 2010). Similarly, nurses in a study by Badger (2005a) mentioned that such families are going through a terrible time in life and sometimes telling them the truth causes conflicts because they don't want to hear what you have to say.

Dealing with families in denial was experienced as a challenge to some of the study participants. Without the nurses' understanding and knowledge of the different stages of grieving, it could be possible for such families to be regarded as trouble makers. During denial, without giving false hope, it possibly will be necessary for the nurses to realize the situation facing the family and try to accommodate them by being patient with them. With time, the family might eventually digest and accept the reality.

3D.6.4 "I don't want this to happen to me"

Once the decision of not escalating treatment had been made, some nurses had difficulties in limiting some of the therapeutic interventions. This is because they did not want the patient to die during their shift referred to in this case as "I don't want this to happen to me". It was believed that it will appear like they have killed the patient and this they explained could haunt them in life. To prevent this, some talked from experience that they would continue some interventions to keep the patient alive until the next shift begins even though they would not record the interventions they carried out on the chart nor report it to the colleague coming to the next shift. Two of them said:

"…sometimes as a nurse you feel like NO, I don't want this to happen to me. You just say no, even if it is a little glucose, I just give. To me it is like now I have killed this

patient so now, I will treat this patient even though I will not write it on the chart. I still remember there was a nurse who refused to start slowing morphine and I was also not going to slow down morphine" (Nurse 15).

"It once happened, the sister who was working there at night kept on purging adrenaline to keep the patient alive. The next nurse came in in the morning and just after we had taken the rounds the patient demises. That nurse was so confused, that "I have just come in, the BP was fine and all of a sudden, the patient demises". They purge quickly, they don't write and you come in, the patient just goes" (Nurse 14).

As experienced by nurses in this study, participants in a study by McMillen (2008) reported that it is generally nurses who actually turn off the inotropic drugs and decrease ventilator support and this was found to be a difficult task particularly for the junior nurses. To some, especially the junior nurses, this was a source of fear that they were accelerating death. As mentioned by nurses in a study by Fridh, et al. (2009a), when death follows end of life decision, it is possible to control the time when it would occur by administering inotropic drugs which makes it possible to postpone the moment of death. In line with the findings in this study, continuation of inotropic support after withdrawal of therapy has been reported by Labram and Hughes (2010) whose participants (1%) felt that inotropes should never be stopped.

Although some did not want this to happen to them, two experienced nurses reported that such practice does not add value to the patient at all as this prolongs the patent's suffering and it was mostly attributed to lack of experience in caring for patients at end of life. They said:

"…it is not adding value, you don't add value. They don't want to feel guilty, feel like they have killed this patient, but indeed the patient is still going to die and they are prolonging the suffering" (Nurse 16).

"It means for the patient to have emotional needs met from the very same staff it is going to be difficult. It is difficult to manage such patient if you don't have substantial

experience. You will keep on purging because you don't want it to happen to you forgetting your colleague that is coming behind. It is going to be a shock that she has killed the patient only to find out that there was no blood pressure" (Nurse 13).

Nurses in a study by Badger (2005b) stated that the hardest thing to do was to keep intervening with a patient who is clearly dying so as to prevent a natural death. It felt like torturing the patient keeping them beyond their time as this did not mean prolonging life but rather just prolonging misery. Similarly, participants in a study by Coombs, Addington-Hall, Long-Sutehall (2012) felt that it was morally wrong to artificially keep a patient with no chance of survival alive.

In this study, it was evident from the findings that some nurses experience difficulty transitioning from curative to palliative care. To them, limiting some of the life saving therapies is almost impossible and they would prefer to continue keeping the patient alive despite the futility. This may perhaps be due to the fact that some nurses do not want to be the ones bringing about death. They would rather have the patient die under someone else's' care than to have him or her die in their hands of care. The other factor that could have contributed to difficulty in limiting some of the interventions and allowing the patient to die without further suffering might be the fear of having a haunting experience that they had 'killed' the patient. To prevent the haunting experience, such nurses chose to keep the patient alive without caring about the fact that they were prolonging the patient's suffering or the unexpected shock from their colleagues taking over from them.

3D.6.5 Little hope

Hope was expressed by nurses in two ways. First, it was challenging when families continued to hope that their relative would recover. Dealing with families who believed that a miracle could happen and that their relative could recover even after the decision had been made was reported to be hard. Due to their continuing faith in patient's recovery, such families kept asking questions that were regarded by nurses to pose a dilemma. In all cases, it was preferred by the nurses not to give false hope and to allow the family time to accept the inevitable. Three of them said:

"The families also are a challenge to us because they will expect nurses and doctors to do miracles. They still have hopes. It becomes a dilemma because in some cases miracles do happen, so you can't say to them the patient will die and then if the opposite happens then they will say you lied" (Nurse 7).

"…they want to hear something different from you. They have been told by the doctor but they still come and ask you hoping to hear something different. They move from one doctor to another even to the nurses they do this also, but we should avoid conveying false hopes about the patient" (Nurse 6).

"…when they ask you the same thing every day, accommodate them. Understand their situation, let them ventilate" (Nurse 22).

Families who continue to hope for recovery despite the patient's poor prognosis and the decision to limit interventions have been reported by Badger (2005a). This author related the families' high expectations to lack of medical knowledge and a lack of understanding about the patient's situation. The author mentioned that it was important not to give any false hope to the family but instead recommended waiting for the family to come to an agreement within a reasonable amount of time. Similarly, Coombs et al. (2012), state that there is a need for families to have time to assimilate information and to move from a position of hope for recovery to understanding the discussions and impact of end of life care.

Secondly in discussing hope, it became frustrating when there was little hope for the patient's recovery but nurses still had to continue some aggressive treatments. Nurses expressed their frustration this way:

"...the orders are not clear, you continue doing the blood gases, what for? If the potassium is 8, so what? Are they going to treat it? So why treat it? You are monitoring the blood pressure, if it drops, so what? Should I give voluven? Are they going to start inotropes?" (Nurse 4).

> *"...the doctors will say it is end of life, but they don't document it. So it is like there is no handover from one doctor to the other so it is overlapping, one here will say there is no escalation, and another one will come and say give voluven. So there is no clear cut like what is end of treatment now"* (Nurse 9).

In line with the findings in this study, nurses in a study by Beckstrand, Callister and Kirchhoff (2006) noted the frustration of continuing aggressive treatments when there was little hope of the patient surviving. They noted that too many times nurses give false hope, offer futile care and run around fruitlessly when they should just stop aggressive measures in a futile situation.

Hope for the patient's survival despite futility as was found to be present among family members in this study shows the families' refusal to accept the inevitable and let their relative go. Apparently the resistance of the family to accept the situation may mean inadequate or lack of early preparation of the inevitable. On the other hand, it could mean that the family might need further explanation or counselling to enhance their understanding of the whole situation. Sudden news may also lead to denial and thus it could be possible that the family in this situation may need some time to come to terms with the imminent loss.

Continuing medical therapies when there is little hope of survival, thus causing frustration on the nurses' side, may imply miscommunication among doctors, lack of documentation and handover. This is thought by the nurses to be so because in some cases, one doctor's orders were found to contradict the other one's orders concerning limitation of treatments. In addition, a prescription to continue active treatment may not make any sense when there are no new interventions to be introduced so as to manage the extreme results

3D.6.6 "Who to call"

The other challenge reported by some of the study participants was who to contact once decision had been made and the family had not been notified or counselled about the decision that had already been made. Normally, the family provide one or two or even three contact

numbers that could be used to reach them in case there is a need but when the patient's condition changes to EOL, nurses did not know exactly who to call. One of them said:

> *"…the other problem I have encountered is who to call in such situations"* (Nurse 13).

Based on who they contact in their respective units, other participants contributed by stating who they usually contact and think should be contacted. Some of them said:

> *"…we always take the closest persons to represent the patient so that we don't divulge unnecessary information to unnecessary persons. It depends, who is the head of this person. You are a child then your mother or father, you are married then it can be your wife or husband"* (Nurse 4).

> *"…they always tell us, when you need something, this is the person you should call first then followed by these three numbers"* (Nurse 19).

> *"In ICU we are so busy, so we ask the family to choose among them who can be the contact person. If anything happens, that is the person we contact* (Nurse 17).

As supported by Gristina et al. (2011), important discussions should ideally involve the same representatives of the patient's family so as to reduce the risk of misunderstanding and confusion. On the other hand, the hospital could develop a guideline to have a designated family member be the representative for other family members so as to facilitate clearer communication process and reduce the stress of many requests for information to the nurse who is providing care (Crump, et al., 2010). The appointment of such a representative should be done as soon as the patient is admitted to the ICU (Davidson, Powers & Hedayat, et al., 2007).

As expressed by some of the nurses in this study, choosing who to contact among the family members was a challenge particularly when they had to move from curative to palliative care. It would be necessary for the units to make it a practice to always ask the family during the

patient's admission to appoint one person to act as the family representative. This would make the nurses' work easy and stress free in terms of having to decide who to contact.

3D. 7 DISCUSSION AND DECISION MAKING

The other major theme that arose from the interviews with nurses was discussion and decision making about transition from curative care to end of life care referred to in these settings as 'not for resuscitation' or 'not for escalation of treatment' or 'palliative management'. Two sub-themes arose from this major theme (refer to **table 3D.4**) and are discussed below:

Table 3D.4 Summary of theme two and its interrelated sub-themes

MAJOR THEME	SUB-THEMES
3D.7 DISCUSSION AND DECISION MAKING	**3D.7.1** "Told not involved" **3D.7.2** "Being on the same page"

3D.7.1 "Told not involved"

When asked whether they are involved in discussion and decision making processes, the nurse participants reported that they are not. Rather, they stated that the doctors often make decisions and once they have made the decisions, they then come to them to elicit about their thoughts about the decision. For example, two of them said:

> *"No, we don't get involved, they discuss, yeah we don't decide, they decide and then they come and tell us we are going to do this and this and that is it. And then they come and tell you, sister what do you think?"* (Nurse 23).

> *"The doctors discuss and after they agree they come and ask you, what do you think sister?"* (Nurse 5).

To support the findings from the majority of the participants in this study, previous studies indicate that physicians are responsible for making decisions about withholding or withdrawing curative treatment and nurses seldom participate formally in decision making

process in spite of their comprehensive responsibility for the patient (Benbenishty, Ganz, Lippert, et al., 2006; Hov, et al., 2007b; Coombs & Long, 2008; Calvin, et al., 2009; Fridh, et al., 2009a). Though rare for nurses to take part in the decision making process in most settings, some studies have indicated active nurse participation in discussion and decision making processes (Ho, English & Bell, 2005; Latour, Fulbrook & Albaran, 2009).

In some cases where the doctors sought the nurses' opinions on already made decisions, the nurses reported that they would give their views and advocate for the patient if necessary. For example, one of the most experienced participants said:

> *"…we don't do the decisions. It* depends *on the doctors, others will just come and turn the knob but others do discuss. And you will tell him, "You know what doctor, you advocate for the patient, why can't you give him time, give him chance, a miracle can happen". At times they accept what we tell them though they might not prolong it too long, they say, "OK let us give him chance""* (Nurse 24).

Other studies mention that senior experienced nurses are recognised by the consultants and they seem to listen to them or are naturally likely to be involved in end of life decisions (Ho, et al., 2005; McMillen, 2008; Coombs, et al., 2012). This is consistent with the reports from a few of the most experienced participants in this study.

While some nurses reported that they share their views with the doctors, most of them felt that doctors do not listen to them and whatever they say does not matter. Due to this, nurses end up agreeing to whatever decision is made by the doctors without arguing because they have no power to disagree. The following examples were given:

> *"We never say no, we just shrug (raises her shoulders and eyebrows). Then they just go ahead and do anyway.* It is nice to be part of the team if they have been listening to me throughout from day one but w*e have realized that our doctors do their own things. They take their own decisions whether you have input or not it doesn't matter"* (Nurse 4).

> *"We are only with the doctor when discussing this is what is happening, we can see, we are not going to order any other treatment further. So it is just that, we don't say yes, please order or don't order or let us give a chance for a day or two or let's change the antibiotic, NO, you can't argue"* (Nurse14).

Despite the reports that poor interdisciplinary communication or collaboration has been reported as one of the barriers to quality end of life care (Downey, et al., 2006; Papadimos, Maldonado & Tripathi, et al., 2011; Rose, 2011; Friedenberg, Levy, Ross, et al., 2012) this still exists. Consistent with the findings in this study, a previous study reported a perceived lack of physician sensitivity to nurses' input in end of life decisions (Benbenishty, et al., 2006). In addition, nurses reported that doctors respected neither their values nor beliefs nor did they listen to them (Calvin, et al., 2009; Hansen, Goodell, DeHaven, et al., 2009; Zomorodi & Lynn, 2010a).

The findings from the focus group discussions in this study revealed that nurses are not involved in end of life discussion and decision making processes. This could be due to the assumption that it is the doctor's role and not the nurses'. Nurses could also be reluctant to join or ask to be involved because they think that the doctors do not listen or value their inputs. On the other hand, the few most senior, experienced nurses mentioned that they always share their opinions based on the decisions already made by the physicians. It may mean that the doctors value nurses' opinions based on their competence, experience and expertise in caring for end of life patients as compared to the junior nurses.

3D.7.2 "Being on the same page"

Despite of the fact that they are not always involved in direct discussion and the decision making process, some nurses in the focus groups mentioned that they would like to be involved. This is because apart from working as a team, they spent the longest time with the patient. For this reason, they therefore felt that they deserve to know and contribute toward decisions regarding patient care as this could enable them to raise their concerns and advocate for the patient where necessary. For example some of them said:

"…things should be discussed about that round there and, at the end of it, you know, everybody should be on the same page" (Nurse 16).

"… it is team work in the ICU and I am most of the time with the patient. Whatever decisions I should also be part of the team so that we discuss it together. I shouldn't feel I am being left out and just being told at the end of it that this is what we have decided. I am part of it, I need to understand where they are coming from" (Nurse 6).

Although the importance of a shared decision making process has been reported in literature (Truog, Campbell, Curtis, et al., 2008; Gristina, et al., 2011; Coombs, et al., 2012), this was rarely practiced in the study settings. Latour et al. (2009) stated that critical care nurses have usually built up a good relationship with the family members, resulting in insights and understandings that provide a knowledge base of the family members in their needs. As supported by these authors and McMillen (2008), this knowledge is essential when it comes to end of life discussions and decisions between nurses and physicians. In addition, Ho et al. (2005) highlight the need of the physicians to initiate discussions with nurses to explain the rationale of their clinical decisions.

Even though it was the wish of the majority of the nurses to be on the same page as a team, a few of them were not willing to participate in the decision making at all. An example given was:

"...not really, it depends with faith in you, other people they pray a lot and have got strong faith. Doctors are people, they decide but in other cases miracles do happen, the patient wakes up. So I wouldn't like to be included, I am not God to know someone's life, I don't want to put a decision when the family still have hope for the recovery of their patient" (Nurse 7).

Similar findings were reported in a study by McMillen (2008); participants reported that the decision to withdraw treatment was not theirs but for the consultant anaesthetist. Reluctance

to be involved in such discussions and decisions could also be associated with individual viewpoints, beliefs and experiences (Coombs, et al., 2012).

From the study findings, the majority of the nurses would wish to be included in the end of life discussion and decision making process. This is due to the fact they are part of the multidisciplinary team hence their need for working together towards a common goal of patient and family care. A few nurses who were not interested in taking part in this process could have felt this way because of their personal beliefs.

3D.8 SUPPORT FOR PATIENTS

Support for patients at end of life emerged as the other major theme. Support in this case implied care directed to the patient that could promote comfort as they approach death. A number of sub-themes arose from this major theme. These sub-themes are presented in **table 3D.5** and a detailed description of each given below.

Table 3D.5 Summary of theme three and its linked sub-themes

MAJOR THEME	**SUB-THEMES**
3D.8 SUPPORT FOR PATIENTS	**3D.8.1** Spiritual support **3D.8.2** "Until nature takes its course" **3D.8.3** Presence **3D.8.4 "**Noise is like normal" **3D.8.5** Patient's advocacy **3D.8.6** Private room

3D.8.1 Spiritual support

All nurse participants reported that spiritual care was necessary for the patient's comfort at end of life. In spite of this, not all of them were comfortable offering such a service. A few of those who were willing said that they offered prayers for the patients provided the family allowed them to do so and so long as they had explained it to the patient. Two of them said:

> *"…we do things consulting with the family as a team as nurses. We do ask the family, can we pray together?"* (Nurse 13).

> *"…we have different gifts in us, so if you feel like God is laying your heart to pray for that patient then you do pray and you can ask other sisters to pray together. As long as the family allow you to pray with the patient, even though they say the prognosis is poor we also get permission from the patient"* (Nurse 10).

At the core of a dying person's experience there is often an overpowering sense of personal loss, with associated spiritual suffering that requires appropriate nursing intervention (Carr, 2008). As an acknowledgement of the patient's spiritual needs at end of life is associated with a peaceful death (Kruse, Ruder, & Martin, 2007), the health care team should assess the patient's spiritual needs and could incorporate the findings into the plan of care (Davidson, Powers & Hedayat, et al., 2007). In line with the findings in this study, the majority of the nurse participants in a study by Labram and Hughes (2010) indicated that religious support should be offered even if not requested while a small percentage of the nurses never offered religious support unless requested directly by the family.

On the other hand, one of those who felt it was not their duty to offer spiritual support said:

> *"It is not our specialty to pray for them, there are people who are there to pray for other people"* (Nurse 2).

Ott (2010) maintain that those who care for dying patients in critical care are often confronted with their patient's spiritual concerns but this frequently makes them uncomfortable because they feel unprepared to address spiritual issues. It has been reported that the chaplaincy service carries the lead position in providing spiritual assessment and care, but all ICU team members have a role in incorporating spiritually appropriate care to those patients and families who have disclosed preferences (Davidson, et al., 2007). Above all, the ability of a critical care team to support a patient's spiritual values and cultural beliefs in the ICU can be used as a quality indicator in end of life care (Papadimos, et al., 2011).

Nurses in this study reported that in some cases, families organize for a spiritual leader to come and pray for their patient. Nevertheless, some patients in the unit may not have any

spiritual leaders or families around. In such instances, one of the study sites had a 24 hour support organization (HospiVision) to be contacted to offer the support. However, nurses reported that it was their duty to organize for a spiritual leader to come and offer spiritual support to such patients. Although this is the case, it was reported that having such leaders to come and visit is not always easy. Therefore, nurses suggested that the hospital should organize a standby spiritual leader to offer such a service if need be. Concerning this, some of the participants said:

> *"Sometimes when we see such things happening, we usually call somebody from HospiVison. The families are also allowed to bring somebody from their church"* (Nurse 19).

> *"…we had to organize for another patient who was in the unit for long and he didn't have relatives around because he was from overseas, but still it was a challenge. The church was asking us from which parish, diocese, church, all those complications. So it was quite difficult"* (Nurse13).

> *"The hospital management should also help to make our work easy by organizing specific leaders to be on standby then we can contact when we need them just to avoid complications" (*Nurse 15).

In line with the findings in this study, lack of spiritual support for patients was a concern cited by some respondents in a study by Hansen et al. (2009). Even though spiritual support is frequently cited as part of individualized holistic care (Ott, 2010), this was not always possible in this study.

Supporting patients facing death spiritually was regarded as important by all nurse participants in this study. While the majority of the nurses offered this support, a few of them regarded it as not their duty. This form of support basically depended on the nurses' enthusiasm and comfort in doing so. In some instances, especially where families did not bring in a spiritual leader or where the patient had no one around, nurses had to organize for a support organization or spiritual leaders to come and offer support. It sometimes proved

difficult for nurses to quickly obtain a spiritual leader to attend to the patient's spiritual needs despite this being their specialty. In such cases, such hardships could be a source of stress to a nurse trying to ensure holistic patient care.

3D.8.2 "Until nature takes its course"

Keeping the patient as comfortable as possible was deemed essential by the nurse participants. To ensure this, the patient needed to be pain free and receiving basic nursing care. This is always continued until the patient dies. Examples given regarding these aspects included:

> *"…the nursing care continues we wash them, change them, feed, do vital signs, turn them, cover them comfortably, we do all the basic things, communicate with them, explain the procedures"* (Nurse 6).

> *"We do everything that you do to a person who has a potential to live. We don't stop, we continue"* (Nurse 11).

> *"We nurse the patient until nature takes its course"* (Nurse 18).

> *"Usually they don't remove sedatives and analgesics. As a nurse you ensure that this patient is not in pain at all by administering these medications as needed. We still give basic nursing care, we suction"* (Nurse 21).

Related findings have been reported by Fridh et al. (2009a) as nurses expressed the importance of considering end of life care as equal in value to the care provided for patients with a good prognosis and keeping the patient as comfortable as possible. As practiced in this study, the importance of verbal communication to critically ill and dying patients has been documented (Alasad & Ahmad, 2005; Hov, Hedelin & Athlin, 2007a).

According to Puntillo, Morris and Thompson et al. (2004), pain is one of most prevalent symptoms in critical care that patients dying in the ICU are subjected to as it is usually

associated with procedures (suctioning, turning, wound care, presence of endotracheal tubes) as nurses aim to keep them comfortable. In Degaldo-Guay, Parsons and Palmer et al.s' (2009) study, 84% of the patients referred to the palliative care consulting team in the ICU were in pain and that 99% of them needed opioid pain management.

The need for provision of effective pain relief has been widely supported in various studies (Downey, Engelberg & Curtis, et al., 2009; Latour, et al., 2009; Papadimos, et al., 2011). Coupled with inadequate training in recognition of pain and anxiety (Friedenberg, et al., 2012) the management of pain in dying critically ill patients may pose difficulties as the common pain assessment tools may be of little value assessing the semi-conscious patient's pain (Cosgrove, Nesbitt & Bartley, 2006). However, the use of a behavioural pain scale or the critical care pain observation tool may assist nurses in objectively assessing dying patient's pain (Payeh, Bru, Bosson, et al., 2001; Gelinas, Fillion, Puntillo, et al., 2006; Efstathiou & Clifford, 2011).

Although nurses wanted to keep the patient as pain free as possible, some expressed concerns relating to the effects of analgesics prescribed to manage pain and promote comfort in a dying patient. They felt traumatised because the analgesic effects caused respiratory distress and hastened death in some situations. For example one of them said:

> *"...they (doctors) say we must give morphine. Morphine contributes to respiratory distress and when you see them gasping, and you keep on pushing morphine to me it is traumatic. But you must give it because, in a way, it is helping the patient to relieve pain but in the other way it is like you are depressing the patient, you are contributing in hastening the patient's death"* (Nurse 3).

Sedative agents given in high doses may be necessary during the patient's final hours to prevent discomfort and reduce pain or dyspnoea; even if, as a consequence, the risk of hastening death is foreseen (Lo & Rubenfeld, 2005; Papadimos, et al., 2012).

Despite the decision to limit aggressive therapies, nurse participants in this study were of the opinion that basic nursing care, including all comfort measures, should be performed until the patient dies. At no point were these patients neglected because of futility. This indicates the nurses' valuing of the patient's dignity despite the prognosis. In addition, despite of the emotional distress experienced due the administration of the analgesics in some patients (opioid double effects), nurses ensured that the patients were not in pain by administering pain medication on time.

3D.8.3 Presence

From their experiences, nurse participants reported that encouraging and allowing families to be present at the patient's bedside acted as a form of support in that patients felt safe, secure and at peace with their families around. Examples given were:

> *"…most of the patients prefer the family members even though they don't say anything. They prefer the love, the support of the family. They expect the family members to give them the care that they know; they are looking at them with those eyes that they feel safe and secured. We encourage the family to come even at odd times. Just come and hold hands, we need somebody to be at peace" (Nurse 13).*

> *"…they must also be involved, caring for this patient is not just from the sister (the nurse), the family must be included in terms of loving. As the patient hears the voice of the family they get stronger every day, it might happen that way, so we encourage them"* (Nurse 20).

> *"…encourage them to bring significant others so that the patient is not alone should the doctor say there is poor prognosis or we are going to withdraw treatment"* (Nurse 14).

Gristina, et al. (2011) mention that the needs and desires of families to be actively present in the final phases of their loved ones' lives should be respected. It has also been reported that nurses appreciate family presence not only for the sake of the patient but also for the purpose

of preparing them as this contributes to the family's preparation and acceptance of the impending loss (Kwak, Salmon & Acquaviva, 2007; Calvin, et al., 2009).

Although it was reported that direct patient care by families is not common probably due to the fear of the ICU surroundings and the patient's state, it was mentioned that some families will want to participate in such care. Nurse participants therefore supported family presence including their wish to participate in direct patient care. This is considered as a way to calm the family, as a source of fulfilment and a way of interaction between the family and the patient. Nevertheless, this had to be done under careful supervision and directions from the nurse so as to avoid mistakes; protect self and the institution. Two participants said:

> *"…she wanted to wash her family member and I gave her space. If they do come forward, we do respect their views but they must do it while we observe and you explain that don't touch this"* (Nurse 12).

> *"You need to be careful as well, your focus will be protecting the institution and yourself"* (Nurse 13).

> *"…if they want to have direct care, we allow them to comb the patient's hair, touch, talk, hold hands, tie ribbons and they interact with the patient in that way. That is what we did last week, it also calms them down to feel that she is warm, they feel that they have been there, they have seen her, they get fulfilment"* (Nurse 18).

Intimate involvement in the terminal care may allow the family to come in terms with the imminent death of the patient and can provide great solace (Labram & Hughes, 2010). Similar to the findings in this study, a survey by these authors revealed that unless relatives express an interest, very few are asked whether they would like to assist with the care of the patient. Nevertheless, families should be encouraged to provide as much care as the patient's condition will allow and they are comfortable providing (Davidson, et al., 2007).

When asked whether they always stay with the patient at the bedside when death is about to occur and where the family is not present, nurses reported that they did not have much time to do so expressed as:

> *"…because of shortage of staff, it is hard when other things are waiting for you. You cannot spend a lot of time with them because there are other things to do like admission and so on"* (Nurse 22).

> *"There is not even enough time because you will be running around trying to find things for the next admission"* (Nurse 23).

Although maintaining presence is one of the ways for nurses to help patients who face death and ensure the likelihood of experiencing a 'good death' (Fridh, et al., 2009a), this was rarely practiced in this study. This is contrary to the findings in a study by Badger (2005a) whose nurse participants always stayed with the patients so that the patients would not have to die alone. Similar to the findings in this study, lack of time due to nurses' shortage has been cited as a factor preventing the ICU nurse from providing quality EOL care (Beckstrand, et al., 2006; Zomorodi & Lynn, 2010a).

In this study, family presence at the dying patient's bedside was promoted by all participants. The families' presence has been associated with preparation for the impending lose and a sense of satisfaction with end of life care. Their presence was also valued as it was thought that patients feel safer when their relatives are around. Even though the families' participation in the care was regarded of importance, none of the study participants encouraged them to do so unless they, themselves requested to take part in the care. This might probably be due to the fear from the nurses that errors could occur that could jeopardize their job as well as the institution. Coupled with nurses' shortage and lack of time, it was viewed as almost impossible by the nurses to always accompany the dying patient (where relatives were not present) as they were required to be undertaking other duties. This clearly reflects the possibility of poor quality end of life care to the patient.

3D.8.4 "Noise is like normal"

Talking from experience, some nurse participants reported that noise has become something normal in the ICU in that you find people making noise forgetting that there are patients in the unit. These nurses believed that such amount of noise does not enhance patients' comfort at all and as a form of support, this needed to be rectified. Two of them stated:

> *"Sometimes the patient is dying but the noise level is like normal, everybody is making noise, they don't care. It affects even the dying patient and the family. The noise level needs to be down, even the people with the presentations around the ward, they mustn't make noise. You hear somebody screaming, shouting, calling somebody as if you are outside in the streets"* (Nurse 12).

> *"…we must observe the surrounding; sometimes the unit does not offer comfort. At times there is lots of activities going on like trolleys, alarms, lights and all other kinds of noises even from the staff. They must be made comfortable by reducing the amount of noise around them"* (Nurse 23).

Noise is a common problem in the ICUs and has been identified as a constant barrier to providing quality end of life care (Pugh, Jones & Griffiths, 2007; Zomorodi & Lynn, 2010a). Staff conversation and alarms are generally regarded as the most disturbing noises for patients in ICU (Xie, Kang & Mills, 2009).

In this study, noise level was reported to be higher and of concern in the ICUs. Although it may not be completely possible to prevent noise due to different and necessary activities going on in the units, it could be possible to minimize such noises so as to promote the dying patient's comfort by ensuring a peaceful environment.

3D.8.5 Patient's advocacy

Due to the vulnerability of critically ill patients and more so the patients at EOL, it was mentioned by the nurses that the patient should not suffer in any way. It was discussed that the patient's dignity should be upheld at all times no matter the prognosis as this patient was

still human and remained humane until death. Being with the patient the longest and putting oneself in the patient's shoes, it was regarded as the nurses' role to advocate for the patient when necessary. Concerning this, two of them mentioned:

> *"…you see the patient is suffering, hence you are proactive to say that the patient should die with dignity, I advocate for the patient to get something for pain"* (Nurse 8).

> *"…advocacy comes in, you are the one in contact with the patient for a longer time so you inform the doctor that this is what I see, can you kindly prescribe something to manage pain. You will be thinking if it was me experiencing such pain, will it be OK? It won't be OK that is when patient advocacy comes in"* (Nurse 14).

The scope of practice of a registered nurse entails the provision of effective patient advocacy to enable the patient to obtain the health care he needs (The South African Nursing Council Act, 1978). Despite the existence of a wide pharmacological range for the relief of symptoms at the end of life, critical care nurses are faced with limitations, such as prescribing and consequently delivering medication timely (Efstathiou & Clifford, 2011). This thus prompts the nurse to advocate for the patient as supported by McMillen (2008). In order for the nurses to advocate for the patients and families in what can often be difficult death and dying scenarios, they need to be confident and have a mastery of the necessary clinical knowledge (Pattison, 2011).

In this study, nurses mentioned that it is their duty to advocate for the patient. This is clearly due to the patient's vulnerability and the fact that the nurse is with the patient longer than any other ICU staff. Bearing in mind their scope of practice, the nurses should be able to assess and pick up when the patient is in distress and need to be made comfortable. For instance, if the patient is in pain, the nurse should act as the patient's voice by asking the doctor to prescribe analgesia so as to prevent suffering and lose of dignity.

3D.8.6. Private room

Nursing the dying patients in single rooms to promote privacy for both the family and the patient was brought up in the focus group discussion sessions. The nurses had different opinions concerning this. The majority were of the idea that the patient should not be nursed in a private room so as to prevent the families' and patient's mentality of segregation. On the other hand, a few of the participants wanted the patients to be nursed in a single room for the sake of the other patients and for the sake of the families' comfort. Examples given included:

> *"I don't think it is a good idea to transfer them to a special area because they will feel neglected. More so, the family will think we don't respect them. They will say they are now pushing him into the side room they really don't want him anymore they don't even want to see him, they are pushing him towards the side"* (Nurse 8).

> *"They should be put in a side ward because sometimes some patients in the unit are awake and they are looking at that patient very ill like that and sometimes we as nurses talk and people around us hear things and it affects them most"* (Nurse 1).

Contrary to the findings in this study, the majority (78%) of the participants in a study by Latour et al. (2009) agreed that the patient and the family should have the privacy of a single room. Davidson et al. (2007) also recommends improvements of patient confidentiality and privacy by building ICUs with single bed rooms that include space for family.

Moving the dying patients to a single room for privacy was not supported by the majority of the participants in this study. They preferred the patient to be nursed with other patients if initially; he or she was not in a single room. Whereas it could imply privacy for some families and reduced fear in the expected to live patients in the unit, this could be attributed to the fact that other families might misinterpret the transfer as a way of disowning the patient due to their nature of illness or futility.

3D.9 SUPPORT FOR FAMILIES

Furthermore, support for families emerged as one of the themes from the focus group discussion with the nurses. The support aimed at caring for families with patients at end of life in the ICU as caring was not only directed to the patients. Several sub-themes were developed from this major theme as shown in **table 3D.6**. Each of these sub-themes is discussed in detail below.

Table 3D.6 Summary of the fourth theme and its associated sub-themes

MAJOR THEME	**SUB-THEMES**
3D.9 SUPPORT FOR FAMILIES	**3D.9.1** Support person **3D.9.2** Respect **3D.9.3** Open access **3D.9.4** "Staying with them" **3D.9.5** Gradual preparation **3D.9.6** Hospitality

3D.9.1 Support person

In as much as the families' initial contact in the ICU would be the nurses and the doctors, the nurses reported that they would wish to offer spiritual, psychological or emotional support but they felt they don't have much time for the family. This is especially when they have other responsibilities to carry out in the unit or more so, when the patient is nearing death or soon after death as they are expected to prepare for the next admission. In this regard, while they can do what they can, nurse participants suggested that there should be specialized persons such as religious leaders, counsellors, psychologists, social workers or certain organizations assigned to offer support to the family throughout in the unit. Some of them said:

> *"We have other disciplines like HospiVision. You can tell them, this family is so desperate. They can come and assess the environment they are in, give them the support, reassure them and pray with them. Psychologists or social workers can also have some input and try to calm the situation because somebody feels so helpless. Where does she go now, such supports must come in"* (Nurse 22).

"…We would love to do that really and we wish may be there was a priest in the hospital that we would call and say please come and pray. We have got this HospiVision. We call them to come and reassure them, they pray with them as spiritual support. I*t will be better if there is a specialized person to do that counselling or so because they are going through a very hard time"* (Nurse 23).

"Sometimes some patients are not from the country or they are from another Province. The family might verbalize that we don't know what to do now. It is good if the social worker can get involved there" (Nurse 10).

Palliative care consultation in the ICU is no longer a rare event (Ott, 2010). As recommended by Davidson et al. (2007) and Bloomer, Tiruvoipati, Tsiripillis et al. (2010), family support should be provided by the multiprofessional team as a way of improving end of life care. In line with a study by Beckstrand et al. (2006), nurse participants suggested that dedicated, specialized team (counsellor, social worker, pastoral staff, palliative care specialist among others) focusing on end of life issues to enhance quality of care be available for consultation if need be.

In addition, it has been reported that family members' desire for spiritual support is very important and ICU staff members should request the services of spiritual care providers who can assist the family before, during and after discussions about clinical decisions and after death (Wall, Engelberg, Gries, et al., 2007; Gries, Curtis, Wall, et al., 2008). This is due to the fact that acknowledgement of the families' spiritual needs at end of life has been associated with greater satisfaction (Gries, et al., 2008).

The need for support persons was raised by the nurse participants during the focus group discussions. It apparently appears that nurses have realized the distress the family undergoes while the patient is at the end of life. Since nurses may not have enough time and skills to attend to the families, they would wish other support persons specialized in some specific areas to assist in reassuring the families.

3D.9.2 Respect

Respecting the patient's and families' wishes, culture, beliefs and traditions was also reported as an important aspect that could form a support system at such a time. Although respect was valued, it was also mentioned by the nurses that not all situations deserve respect and as a nurse, one needs to judge the situation before allowing certain practices to be carried out by the family. Some of the aspects that were respected and supported as reported by some the nurses included:

> *"…other patients have preferences, we can hear it from them or we can hear it from families. Others have advanced directives so sometimes we work based on that"* (Nurse 13).

> *"We respect the patient's culture and beliefs. If they believe in inyangas then let them have them around, not only the religious people. We give them the opportunity to practice their beliefs as long as they don't affect other patients"* (Nurse 6)

> *"Sometimes when the patient has died family will want to come and take the spirit. And on that bed there is somebody already who belongs to another culture. You explain to this other patient that they are not for you, so we allow them to do so"* (Nurse 16).

Due to the fact that in the crisis of life threatening illness it can be difficult to determine the patient's preferences and wishes in the cases where there is no completed advanced directive (Crump, et al., 2010), the family is often asked to represent the patient (Cohen, Sprung, Sjokvist., et al., 2005; Frost, Cook & Heyland, et al., 2011). On the other hand, living in culturally diverse communities, cultural attitudes of the patient and family need to be addressed and respected as well as giving the patient an opportunity to receive the last rites according to their religious and spiritual beliefs as these may help many patients and families to cope with illness, death and dying (Davidson, et al., 2007; Latour, et al., 2009). Moreover, continued support is necessary for the family even after the patient's death with specific needs depending on individual and cultural characteristics (Carey & Cosgrove, 2006).

Some of the families' requests or practices were thought to be hazardous to the patients, staff including the institution and these were not entertained. Three of the participants said:

> *"...at times, it is very difficult, the family will say we have been told the prognosis is poor. They try to corner the doctor into pulling off; we don't know what they benefit from this. Sometimes we have siblings, the other one want the parent to live, the other want us to withdraw treatment. So where does it lead us? If nothing is written, there is nothing that we can do; it is a sort of a dilemma. But if there is a division between the families the doctors must call them together so that they explain to all of them, what they decide, I think it will be up to them as a family "*(Nurse 15).

> *"I once experienced the relatives came in, they closed the curtain around the patient and then there was fire. You know it is dangerous with the oxygen port. That is why I am saying, it is their culture but it is also dangerous"* (Nurse 10).

> *"…some of them we can't, like if they want to come and give muti or something to drink"* (Nurse 21).

Patient's family members' disagreement about treatment decision making and the hardship for staff to get them all on the same page have been reported in previous studies (Badger, 2005a; Carey & Cosgrove, 2006; Friedenberg, et al., 2012). In such instances, even if the patient has an advance directive, a lot of time the families will step over that and change the patient's code status on the basis of the family members' own needs (Badger, 2005a). In terms of cultural beliefs and practices, it has been indicated that performance of rituals can only be supported if they do not interfere with the care of other patients and their families (Carey & Cosgrove, 2006).

While respecting the patient's and families' wishes, culture and traditions was thought to be important by the participants in this study, nurses mentioned that not all wishes or cultural practices would be regarded as safe. Dealing with culturally diverse population, it is evident that nurses have a hard task in trying to accommodate each and everyone's beliefs in the intensive care environment. This is true because some cultures will come up with risky

traditional practices that may endanger the patient, the nurses' job and the hospital at large. It would thus be concluded that the nurse should always be alert and careful when it comes to which wishes or practices to be allowed or not to be allowed in the unit.

3D.9.3 Open access

In all the participating hospitals, families of patients at end of life were allowed to come in to the unit to see or stay with their patient any time they wished. They would only be requested to leave shortly whenever certain procedures requiring privacy needed to be carried out in the unit. Open access was considered to be of importance by the nurses as it could be the last time for the family being with the patient. This was expressed as follows:

> *"…if they want to come in 24 hours it is allowed. We frequently tell them to come and stay with the patient as they wish. It might be their last moments together so we are trying to be understanding"* (Nurse 4).

> *"…they can come in any time they want and as long as they want. But when you do a procedure that needs privacy, you let them go out"* (Nurse 19).

The importance of open family visitation has been documented in literature (Davidson, et al., 2007; Bell, 2011; Noordemeer, Rijpstra, Newhall, et al., 2012). For example, flexible visitation decreases the patient's anxiety, confusion, agitation, makes the patient feel more secure and it increases patient satisfaction. On the other hand, unrestricted visitation increases family satisfaction, decreases family member anxiety, promotes better communication and it contributes to better understanding of the patient. As was valued in this study, the majority (91.3%) of the study participants in a study by Latour et al. (2009) felt that the family should visit any time of the day or night without restriction on the number of visitors (57.1%) or the length of time of their visit (86.9%).

Families' open access to the dying patient was valued by all the participants in this study. It is clear that the participating hospitals and more so, nurses realized that the patient's last moments were precious to the family. In this regard, unrestricted visitation rules had been set

for all families with patients at the end of life. The families were allowed to come in any time they wanted apart from when certain procedures that needed privacy had to be performed. Open visitation could not only be associated with sharing the last moments together but it could also be a source of family satisfaction with end of life care as well as to the dying patient.

3D.9.4 "Staying with them"

Most nurses mentioned that it was necessary to create some time to be present ("staying with them") for the family while they visit the patient as this could raise the families' confidence in the type of care the patient is receiving. The nurses' presence could also be used as a way of reassuring and orienting the family about the surrounding. For example, some said:

> *"I wouldn't say that we stay with them in the room, if they find me in the room, sometimes they are anxious, shocked they don't know what to say, what to do. I always explain or refer them to the doctor. I tell them they can hold hands, talk to the patient, pray if they want, because I always believe that the mind is the last thing to die so if they talk the person lying there can still hear"* (Nurse 11).

> *"It is better if the relatives find you in the patient's room. At least you should leave after you have explained anything because they will have got that confidence that the patient is being looked after than not to find somebody there. They will start to say there was nobody there, the patient was neglected and left alone. You reassure, stay and talk with them because they have a lot of questions"* (Nurse 15).

> *"…like the machines, the relatives won't understand, the sister (nurse) has to stay with them and explain to them what they are doing. When a patient comes in, before we reach the terminal stage, we orientate the family about the surroundings of the patient, the monitors, how it works, what those lines represent. So when that time comes, they already know the environment"* (Nurse 23).

One of the most fundamental roles nurses play in providing emotional support to families is being present at the bedside, providing comfort, a caring touch and a listening ear (Bach, Ploeg & Black, 2009; Coombs, et al., 2012). The nurses emphasised the importance of being present to support, comfort and orientate the family, which is in accordance with previous studies whereby nurses supported and encouraged families to touch and talk to the patient as well as describing the ICU environment and medical devices to them (Hov, et al., 2007a; Fridh, et al., 2009a).

Although this was the case, nurse participants reported that frequently, nurses especially the junior nurses will leave the family alone in the room intentionally because they are not prepared to handle the family. An example given was:

> *"…sometimes when relatives come in, the nurses disappear. They don't want to be asked questions. Some say this family is very difficult, they like asking questions. Most of the time it is the junior nurses who tend to disappear, they are not yet competent. But experienced people will be able to stand with the family"* (Nurse 14).

According to Finfgeld-Connet (2006), nursing presence results in enhanced mental and physical wellbeing for the recipients but in order to provide it, the nurse must be personally and professionally mature. In a study by Thacker (2008) and Zomorodi and Lynn (2010a), the more expert and experienced nurses indicated confidence, maturity and an ability to adapt and change to specific situations as end of life care in the ICU became more comfortable with each exposure. On the other hand, it was found to be more difficult for junior nurses to express their views due to their lack of confidence (McMillen, 2008).

In addition, nurses' presence when death is about to occur was valued by some of the nurses although some mentioned that they may not be able to stay with the family for longer period of time. A few of those who valued their presence with the family when death nears said:

"I stay if they are comfortable, I ask them, do you want me to stay with you or should I leave you alone? Sometimes you find families will want that quiet moment alone with the patient, others want to do their last respect and may need privacy" (Nurse11)

"We stay and talk with them. They cry, we give them some shock mixture to calm them down. Then we can now leave them when we have seen that they have calmed down. We give them some chance alone, we give them their space" (Nurse 23).

Just like these nurses stayed with the families, the nurses in a study by Fridh et al. (2009a) considered it a privilege to accompany the patient on their last journey together with the close relatives. Elsewhere, families voiced that staff should ask families if they would like someone to sit with them (Kirchhoff, Palzkill & Kowalkowski, et al., 2008).

On the other hand, the majority felt that there was no time completely as they will be busy doing other duties or are expected to prepare for the next admission. For example two of them said:

"…they (family) sit with him (patient), hold their hands, while I run around looking for the shroud, this and this. There is no time because somebody else, the surgeon has already asked for the bed, so they are counting on this bed now" (Nurse 8).

"…while the relatives are there, I am looking for the pump for an admission that is coming on this bed. So really I cannot be there with them because I have got other things again to do. We would love to do that really" (Nurse 4).

Lack of time due to nursing shortage or other assignments in the unit have been identified in literature as one of the obstacles to providing quality end of life care and meeting the needs of the grieving families (Beckstrand, et al., 2006; Crump, et al., 2010).

Different opinions were raised concerning being present or staying with the family at the bed side as a form of support in the focus group discussions. Even though they could not stay

with the family throughout, it could be true that those nurses who created some time and were willing to stay with the family understood the families' need of a shoulder to lean on. Their presence, orientation and reassurance of the family portrayed their maturity and competence in the caring for the dying and their families.

On the other hand, it is possible that the units could be always busy considering the nurses' shortage in this context. This may have largely contributed to insufficient time to fully attend to the family and the dying patient. In addition, it might be concluded that lack of knowledge, skills, competence and experience in end of life care might possibly put nurses in a fixed situation of not knowing how to attend to the family hence the habit of disappearing when the family is present in the unit as a way of avoiding to be confronted.

3D.9.5 Gradual preparation

As had been observed by some of the nurses, families were not prepared in advance concerning the patients' progress. Preparing the family gradually in terms of information giving was thus considered as another form of support that nurses and more so doctors needed to ensure. As suggested, this needed to start from the first day of admission in order to prepare the family on what to expect at the end while at the same time conveying information in a way that could be easily understood by the family. Some participants said:

> *"I have realized that the family is not prepared days before. They will just be called on that particular day when the patient is going to die. For me I should say they need to be told from day one by the doctor. Explain to them every day about the prognosis. Just to prepare them for that. Even the language, everybody needs to come down to the level that can be understood."* (Nurse 12).

> *"…transparency is very important. They must have the knowledge of the situation we are in so that they can rest, so that we can gain their cooperation and then they can gain the understanding. The doctor should prepare them gradually. Tell them this patient's condition is getting worse so at least they know what is about to come"* (Nurse 21).

"…we must involve the relatives immediately after we admit the patient. We should communicate with the relatives and call the doctor just to discuss the prognosis of the patient so that it won't be a shock if it is at that stage" (Nurse 15).

Adequate communication is an important determinant of satisfaction with end of life care in the ICU (Cohen, et al., 2005; Downey, et al., 2006). However, it has been reported that the challenge to critical care team is in implementing communication, openness and honesty which are the skills that could lead to clear decisions that satisfy the needs of all parties and ultimately to quality care (Hurley, 2010).

Similar to the findings in this study, inadequate family preparation has been reported by Zomorodi and Lynn (2010a). On the other hand, it has been documented that while avoiding medical jargons (Davidson, et al., 2007; Shannon, et al., 2011), effective communication with patients and relatives should begin as soon as possible after ICU admission (Levy & McBride, 2006; Gristina, et al., 2011). As recommended by Davidson, et al. (2007) and Papadimos, et al. (2012), family meetings with the multi-professional team should begin within 24-48 hours after ICU admission and repeated frequently as dictated by the condition of the patient.

It had also been noticed that when doctors counsel or give information to the family, nurses do not attend such meetings. This was also noted by the researcher who attended a couple of meetings with family and the doctor and there were no nurses attending. Nurse attendance as mentioned could ensure that they also understand what message has been conveyed to the family and in some instances would help interpreting in a way the family could understand better. For example two participants stated:

"When a doctor communicates with the family, as a nurse you should be there to put it in a simple way. To explain it in a lay man language so that the family can understand, but we rarely attend" (Nurse 10).

"Even nurses need to come in during the explanation" (Nurse 12).

Although it was not practiced by nurses in these study sites, family meetings should be done with input from all pertinent members of the multi-professional team (Davidson, et al., 2007). As family satisfaction and ratings of quality end of life care are linked with good communication, a shared decision model is advised as appropriate to improve communication, with collaboration between physicians and nurses and ultimately between health care professionals and the patient/family (Efstathiou & Clifford, 2011).

Through experience, some of the nurse participants in this study noted that the families do not receive early preparation about the patient's prognosis and progress. The need for regular family meetings and updating from the first day of admission could be a way of informing families of what to expect so that it does not become a shock to them in case it turns out that the patient may not recover.

Another significant observation made was that nurses do not always join the family and doctor's meetings during the discussion of the patient's prognosis and treatments even though most of their time is on patient and family care. Several reasons behind this could be drawn. Firstly, it could be due to the mentality that it is the doctor's role to offer explanations and progress report about the patient. Secondly, it could be that the nurse is busy with the patient and may not have time to attend the meeting sessions. Nevertheless, being part of the team, the nurse could gain or share information and help to simplify the information provided to the family in an understandable way during and even after the meeting when they interact with the family at the bedside.

3D.9.6 Hospitality

On the other hand, kindness towards the family from the nurses was raised as an imperative source of support to the family. To show their hospitality to the family when the patient was in the dying process, nurses reported that they practice a number of things as stated:

> *"When we know the patient is going to die we call them in, the doctor speaks to them, we allow them to sit by the patient's bedside, offer them anything that they might need*

like tea, if they have anything to ask we can manage that if we can, or we refer them to the doctor. We help them as much as we can" (Nurse 11).

"…they just need a shoulder to lean on. The best I do at such a time is a hug, sometimes you just give a chair and it shows you care, they feel comforted if you do such things" (Nurse 13).

"...you empathies with the family. You say to yourself, if this was my mother, my father, my brother here who is dying, how would I feel? You actually feel for this person it doesn't matter whether you know them or you don't" (Nurse 17).

Whereas providing excellent care to dying patients and their families require compassion (Otto, 2010), displaying empathy conveys humanity and matters to families (Longden' 2011:134). Similar to the findings in this study, a sense of empathy towards the family with a patient at end of life has been reported by Badger (2005b) whereby nurses kept picturing their loved ones and it kind of gave empathy towards the family and the patient.

Treating the families with kindness was reported to be important by nurse participants in this study. This form of treatment could portray empathy and feelings of humanity in the nurses. This is in the sense that they put themselves in the families' positions and from this they are able to handle them as they would have loved to be handled in return. This form of support could probably keep the families comforted and reassured just to know there is someone who cares about them.

3D.10 SUPPORT FOR NURSES

While nurses care for the patients at end of life including their families, which is a process that was reported to be difficult and challenging, the nurses reported that they also need to be cared for and supported through various ways. These forms of support which arose as sub-themes from the major theme are summarized in **table 3D.7** and discussed in the following section.

Table 3D.7 Summary of theme five and its associated sub-themes

MAJOR THEME	SUB-THEMES
3D.10 SUPPORT FOR NURSES	**3D.10.1** "Just to talk with somebody" **3D.10.2** Team work **3D.10.3** Training **3D.10.4** Shift changes **3D.10.5** Time to adjust

3D.10.1 "Just to talk with somebody"

The experience of caring for the patients at end of life as well as their families as reported by the nurse participants is difficult and challenging both mentally and emotionally. As a form of support, nurses mentioned that their emotional and psychological disturbances could be lessened if they could talk with someone (apart from their colleagues) during the caring process and or after the patient's death. Even though they are not currently provided in the participating units, counselling or debriefing sessions were suggested as an important source of support for all nurses. In connection to this, some of the study participants said:

> *"…nurse counselling session, not necessarily that you are having problems but just to talk to someone and offload yourself because you are not just a nurse, you are a mother, you are a family member. May be something like debriefing session because such discussions can improve in the nursing care, it will discuss how best we can handle such cases"* (Nurse 18).

> *"…nurses should be debriefed but it is not practical because the things that we get exposed to on a daily basis are deep but there is nothing done to us. We end up surviving. You survive and then you become desensitized to what is happening around you. It is also important as colleagues to assess the emotions and feelings of other colleagues"* (Nurse 2).

> *"…you are expected to admit another patient and just carry on as if nothing has happened, there is no debriefing, there is nothing expected. At least after the patient has died someone should come and talk to you. For a healthy nurse to be able to take care, she will also need to be cared for so that she cares for other people effectively.*

So post the patient has died someone should say this has happened, so how do you feel? In future, how can we deal with this?" (Nurse 14).

It has been shown that after a patient dies, nurses may grieve and if grieve is concealed or suppressed it may lead to further stress which may undermine the effectiveness and quality of care offered (Calvin, et al., 2009). Truog et al. (2008) acknowledge that health care professionals have important bereavement needs. In order for nurses to cope with end of life situations and be able to undertake the challenges of providing end of life care confidently and competently, formal or informal timely debriefings should be conducted (Cosgrove, et al., 2006; Davidson, et al., 2007; Pattison, 2011).

Being human, nurse participants reported that caring for end of life patients is a stressful experience. Despite of being stressed and undergoing sorrow, it was reported that there is no form of support offered by the institution. This could mean that some nurses either talked or shared their experiences with their colleagues while some might have just suppressed their stress and continued with nursing care. This as has been shown could cause detrimental effects on effectiveness and quality of care. This thus raises the need of support system whereby nurses can air and share their feelings with other support persons hence reduced stress level and eventually increased quality patient and family care.

3D.10.2 Team work

On the other hand, nurse participants mentioned that team work is lacking in most of the units. They mentioned that the ICU staff must have team work while they care for the patients at end of life including their families as a form of support for one another. In order to ensure quality care, there was a need to assist each other and do away with favouritism which was found to be common in the units. For example two of the participants said:

"…the ICU team must have team work, we must have one spirit, we must be cooperative, we must have understanding" (Nurse 21).

"…we don't work with favourites, favouritism must be resolved so that we can support each other in caring and to ensure quality care because you won't be struggling alone, you won't fight alone, others will boost you when you need them" (Nurse 20).

It is clear that accomplishment of good nursing care for the dying patients depends on caring teams' cooperation (Hov, et al., 2007a). When cooperation occurs among the interdisciplinary team of care providers, the decision making process is appropriate and the quality of end of life care is good (Gristina, et al., 2011). Contrary to the findings in this study, nurses in a study by Badger (2005b) reported that they had a great team in which they were all close to each other while they dealt with life and death.

Division and lack of team work in the ICUs as was reported by the nurse participants was regarded as a common problem while caring for patients at end of life. The lack of collegiality among the staff especially among nurses themselves could be related to one's attitudes, personal background including one's personality. These non-cooperative behaviours could ultimately be a source of stressful working conditions hence poor quality patient and family care.

3D.10.3 Training

It was mentioned by some of the nurse participants that from what they have experienced, nurses may not have substantial experience in caring for the dying in the ICU. Training was thus suggested as the other form of support. This was for the purpose of enlightening nurses on not only how to handle patients and families in such situations but also how they, themselves can cope with the challenges they come across in the caring process, more especially for the junior nurses who find the whole caring process stressful. Three of them said:

"What substantial experience are we having? Do we have that substantial experience caring for the dying? We don't have that experience of how to deal with the emotional experiences of families" (Nurse 13).

"…offer some end of life care training on how we can go about handling families and patients at such a time. With us seniors we are much better. Junior nurses are the most affected, they get a lot of stress and trauma. They need somebody to support them." (Nurse 20).

"…give us stress management sessions because it is a stressful experience we undergo" (Nurse 24).

It has been indicated that delivering good nursing care to patients and families at end of life depends on the nurses' competence and knowledge of palliative care principles (Hov, et al., 2007a; Efstathiou & Clifford, 2011). Unfortunately, critical care nurses have not received adequate educational preparation for delivering care to dying patients and their families (Kirchhoff, Beckstrand, & Anumandla, 2003; Mallory, 2003; Beckstrand, et al., 2006). Due to their lack of knowledge, autonomy and support with providing end of life care, nurses report frustration (Ciccarello, 2003). For this reason, all members of health care team need additional education on the many issues surrounding end of life care (Beckstrand, et al., 2006; Davidson, et al., 2007; Thacker, 2008; Hansen, et al., 2009; Schlairet, 2009; Crump, et al., 2010). While nurses experienced in caring for the dying patients in the ICU are often highly skilled, an emphasis has been put that junior nurses may need specialist training to help them ensure that they can acquire these skills (Pattison, 2011).

From the findings in this study, it is clear that nurses are neither comfortable nor well prepared in tackling different challenges during end of life care. This is mostly in relation to the insufficient training and lack of knowledge on how to go about while handling such situations. For this reason and as per their wish, it could be important if the nurses caring for such patients in the ICU receive special training sessions on palliative care. More so, the junior nurses could mostly benefit from such programs as it could improve their knowledge and competence in caring for patients at end of life and their families.

3D.10.4 Shift changes

Although some patients die within a few hours, in a number of situations after the decision has been made, some could be gasping for days. Due to certain patients' death occurring days later, it was suggested that it could help if the allocation could be made in such a way that a nurse changes from one patient to another to prevent emotional drain. An example given was:

> *"…they can be gasping even for two days. If yesterday you looked after this patient and you are so emotionally drained, let somebody take over and nurse the patient and see how they cope. And if you are not coping with that type of patient they should change you to another patient because other people we are so weak emotionally we just break down"* (Nurse 11).

These findings are in line with the findings by Badger (2005b) who report rotating through, and taking turns in the caring of end of life patients as nurses' coping strategy. This is because transitioning to end of life care could take hours or even days or weeks (Coombs, et al., 2012). Although shift changes were raised as a form of support, other studies are inconsistent with this idea. For example, in one of the studies, most nurses (77.0%) agreed that the patient should continue to receive care from nurses who know the patient and the family (Latour, et al., 2009).

Another concern was the need to put into consideration the nurses who have just been bereaved during delegation of duties. It was suggested that as a form of support, such nurses should not be allocated to such patients as soon as they come back from bereavement. This, as believed could remind them of what just happened which could contribute to emotional disturbance. Two of them said:

> *"…you have just come back from bereavement and they allocate you this other patient who is at the end of life, it is your first day and delegation is there, you must. Such things we need to consider them because you might not cope"* (Nurse13).

> *"I think it is a good thing to look at which patient to allocate to somebody in that state, we differ, others will forget all about it and carry on while others it will be hard*

and a constant reminder to them and you see them going to the toilet several times and they come out wiping their eyes, red eyes" (Nurse 22).

Similar to these findings, being mindful that not all nurses will wish to engage in end of life care, particularly those who might have recently experienced loss, it is important to ensure that units foster a nurturing, caring environment to support the whole multi-professional team (Pattison, 2011).

The fact that nurse participants in this study raised the need of shift changes in certain situations could imply that the nurses are emotionally affected when caring for patients at end of life. Continuity of care in this state may not be possible as this could drain them the more. This thus means that the units should ensure that they assess the nurses' ability to cope with the situation and intervene where necessary for the sake of their emotional wellbeing.

3D.10.5 Time to adjust

After death and before the next admission, it was the nurses' wish in the focus group discussion to be given some time to adjust. Occurrence of death was mentioned as a source of psychological disturbance and the nurses' alertness was decreased in case they needed to admit a new patient immediately as they were not given time to adjust. This was expressed as follows:

"…after it has happened, there is an admission. They need this bed for another patient and you find you are not alert. Your brain goes back, and you slow down, because you are still disturbed, you were not given time to adjust" (Nurse 21).

"Seeing the patient going down until the end is the most draining part and thereafter, you are expected to admit another patient and just carry on as if nothing has happened" (Nurse 14).

Comparable findings have been reported by Fridh et al. (2009a) whereby end of life care was experienced as exhausting and the nurses reported that afterwards they often felt drained and needed time to recover before they could care for new patients. Staff shortages and the severe shortages of ICU beds, especially in the public sector (de beer, Brysiewicz & Bhengu, 2011) coupled with the fact that South Africa, has a quadruple burden of disease due to the presence of patients' co morbidities including HIV/AIDS and Tuberculosis, other acute illnesses with a high incidence of chronic disorders including hypertension, diabetes, cancer, kidney and cardiac illnesses (National Health insurance, 2009) may be against the nurses' wish to have time to adjust in this study.

The results in this study revealed that nurses would wish to have time to adjust in between the patient's death and a new admission. It is clear that such a need could not have been easy to attain in this setting given the limited resources (both nurses and beds). Moreover, it could be that due to the country's increased number of most sick patients, there is an increased demand of ICU beds in such a way that new patients are admitted to the units as soon there are vacant beds.

3D.11 CONCLUSION OF THE FINDINGS

The findings from the focus group discussions provided are a representative of intensive care nurses' experiences of end-of-life care in the ICU. The discussions highlighted a number of important issues that nurses come across while caring for the patients at end-of-life including their families. These issues ranged from difficulties encountered during the caring process to ways in which they can be used to offer support to not only the dying patients but also to their families and the nurses involved in the care.

One of the major themes that arose was challenges. Nurses reported that it is challenging to care for the patients at end of life including their families and this was expressed in various ways. To begin with, nurses found it challenging psychologically and emotionally especially when they had to care for younger patients or patients that had been in the unit for a longer period. The difficulty of letting go was associated with the bond that had developed between the patient and the family. As humans, nurses also felt emotionally disturbed expressed as

painful, heartbreaking and draining among others when they saw such patients suffering and slowly dying.

In terms of communication with families, the nurses had difficulties concerning whether to talk to them or not about the patient's prognosis and progress. While it was thought that talking could lead to confusion and misinformation, nurses also thought that it was tricky because the family could use their words to put them in a 'corner' or trouble. In most cases, they would refer the family to the doctor for any explanations needed. The other reason given as to why nurses were reluctant to talk is because it was not in their scope of practice to do so.

On the other hand, dealing with families in denial was also reported to be a challenge. Whereas a few regarded such families as troublesome, the majority tried to accommodate them as they understood that it was part of the stages of grieving and that families needed time to come to terms with the news. Despite the need to end patient's suffering, it was not easy to initiate limitation of treatment especially in patients who had been in the unit longer and had developed relationships with the nurses.

A few nurses generally found it totally difficult to start limiting life sustaining therapies such as inotropes. The reason behind this is that such nurses did not want the patient to die under their care. They stated that if the patient died it would haunt them. This meant unnecessarily keeping the patient alive and prolonging suffering which was regarded by the majority as not adding value to the patient at all. On the other hand, nurses expressed desperation when the doctor's orders were not clear. Having to continue some activities such as blood gas analysis and continuous monitoring despite of little hope for survival was frustrating.

The other challenge experienced by the nurses was about who to contact when they had to move from curative to palliative care. Even though they normally have at least two or three contact persons on the patient's chart, it sometimes became hard for them to decide who to call. In such cases, some nurses suggested that the family should appoint one family member

to act as the family representative. This person should be the one to be contacted in all situations if need be and he should be the one to liaise with the rest of the family.

Of much significance from the focus groups also was end of life discussions and decision making. When asked whether they are involved in end of life discussion and decision making process, nurses reported that they are not. Rather, the doctors make decisions and thereafter, they come and ask them of their opinions. In addition, it was found that a few most experienced nurses shared their opinions concerning the decisions that had already been made. In most cases, nurses agreed with decisions made without arguing. This was because of the fact that doctors do not listen to them nor value their inputs.

Nevertheless, nurses mentioned that being a team, they would like to be involved in the discussion and decision making process. Involvement would ensure that they can also share their ideas concerning the goal of care considering that they are the ones with the patient and family much longer time than any other staff. Despite of this, a few nurses did not want to be involved because they are not God to determine someone's life span. They believed that miracles do happen and sometimes even if doctors say the patient may not survive, some do come up.

The other major theme that came up from the focus group discussions was support for patients. This form of support implied to all those activities that would ensure patient's comfort in the dying process. As religious and spiritual support has been associated with a peaceful death, this form of support was supported by all nurse participants. Whereas it was supported by all, not all of them were willing to offer this support. Although some of them were comfortable praying for the patients having consulted the families, a few mentioned that it was not their duty. In most cases, it was preferred to either ask families to bring their own spiritual leaders, organize for those patients who did not have families or arrange for some support organizations such as HospiVision to come and offer spiritual care. Because it was not always easy to get hold of spiritual leaders for those patients who did not have any, nurses suggested that the hospital should organize a specialized person on standby to be conducted when need be.

Without neglecting and until nature takes its course, nurses reported that they do offer basic nursing care to patients at end of life just like any other patient with a chance of survival.

Above all, nurses mentioned that it is their duty to assess and minimize suffering by keeping the patient pain free all the time. To achieve this, nurses said they administer analgesics and sedatives as prescribed or when needed despite its double effect that could result to respiratory depression. Where not available, patient advocacy for prescription of these medications as reported comes in.

Additionally, family presence and participation in direct patient care was regarded as the other form of patient support. Families' presence was considered as not only a way to ensure that the patient is not alone during the dying process but it also acted as a way of gradually preparing the families to the imminent lose and a source of satisfaction with end of life care. Although nurses did not encourage families to participate in direct care, they reported that they always allow them to participate if they raise their desire to take part. The reason as to why they did not often ask families to take part was because of the fear that families may make mistakes that could risk their job and the institution. On top of these, nurses' presence with the patient was also viewed as important to the patient. In spite of this, not all nurses were able to do so because of nurses' shortage and lack of time as they were expected to conduct other activities out of the patient's room.

Moreover, it was noted that the noise level in the ICU is higher. Lowering the noise level of especially from the staff would ensure a quite surrounding hence a source of comfort to the patient. Apart from this, the minority of the participants suggested the need for a private room for the dying patients, families and other patients' privacy. Those who were against patients being taken to a private room mentioned that it was because the family would feel that the patient is being deserted and disowned.

Support for families appeared as the other most significant finding. This type of support involves all the actions that could make the families feel better even if it is emotionally draining and difficult to lose a close relative. Given the fact that nurses are mostly busy, they raised a need to have specialized support persons such as a spiritual leader, social worker,

psychologist or support organizations to assist in comforting and reassuring the families. Bearing in mind the peoples' cultural differences in the present society, it was mentioned that patients' and families' wishes including practices of rituals should be respected. Even though this was the case, these practices would not always be valued especially where it could result in negative effects to other patients or the hospital.

Furthermore, open visitation was advocated by all nurse participants. In terms of accompanying the family when the patient's death neared, a few nurses reported that they would ask the family if they would like them to stay in the room for support. Due to limited time, most of them said it was not possible to stay with the family in the room because they had other assignments to carry out. Nonetheless, they were willing to make them as comfortable as possible before leaving them in the room by offering them whatever they needed such as tea, chairs, shock mixture or water among others.

Through experience, nurses had noted that often families do not receive early preparation concerning the patient's prognosis. It only came as a shock at the end when they were told that the patient may never survive. The nurse participants suggested that the doctors should start informative meetings from the first day of patient's admission so as to prepare the family of what to expect. At the same time, it was reported that nurses do not attend while such meetings are being conducted. The need to be present in the meeting was stressed as this could ensure that the nurse knows what is going on hence the ability to support the family in terms of clarifying information during the meeting or afterwards at the bedside.

Lastly, support for nurses emerged from the focus groups as the other major theme. From the findings, it is clear that nurses face a lot of challenges and difficulties while caring for patients at end of life and more so the families of such patients. Some of the challenges experienced as mentioned earlier included psychological and emotional distress, lack of strategies of dealing with families, insufficient knowledge and experience in end of life care including lack of support from the institution. To overcome these challenges, nurses mentioned that they also need to be cared for and supported in order to be able to holistically care for the patients and their families. In the list, nurses mentioned the importance of

debriefing sessions, training, team work, shift changes and time to adjust in between a patient's death and a new admission as ways that could support and enable them to cope.

Generally it could be concluded that for the patients at end of life to be comfortable and have a 'good' death, there is a need for different aspects of support from both the ICU team and the family. In order to attain this, all the ICU multi-disciplinary team should work in collaboration with the family towards the same goal and plan of care. Similarly, while families of such patients face a tough time, the care and support should extend to them so as to enhance satisfaction with end-of-life care and reduce the stress level. On the other hand, the management (starting from the lowest unit management to the highest) should bear in mind that while nurses do care for the patients and families, they too need to be nurtured in order for them to provide quality end-of-life care. Without the required support for nurses, burn out will result and eventually poor patient and family outcome.

3D.12 SUMMARY

This chapter presented the methodology and the findings from the focus group discussions that were conducted with the intensive care nurses. Biographic information of the participants, discussion of major themes and sub-themes arising from the focus groups including the conclusion of the findings and a summary has been provided.

The following chapter deals with best practice guideline development on end-of-life care.

CHAPTER 4
BEST PRACTICE GUIDELINES FOR INTENSIVE CARE NURSES ON END-OF-LIFE CARE

4.1 INTRODUCTION

In the previous chapter, the research methods and design including the findings and discussion of the major themes that arose with regard to intensive care nurses' experiences of End-Of-Life (EOL) care in the Intensive Care Unit (ICU) were provided. This chapter implies to stage II of the study. In it, the methodology and the tentative Best Practice Guidelines (BPG) for intensive care nurses on EOL care have been developed and presented. An outline of the conclusions drawn from stage I (step 1-4) is provided. In addition, conclusions integrated and synthesized from step 1-4 including the developed recommendations is provided **(Table 4.2)**. Finally, each of the developed recommendation is categorized according to its strength of evidence and thereafter supported by a discussion of evidence. Refer to **figure 4.1** for the summary of the process of conducting this chapter.

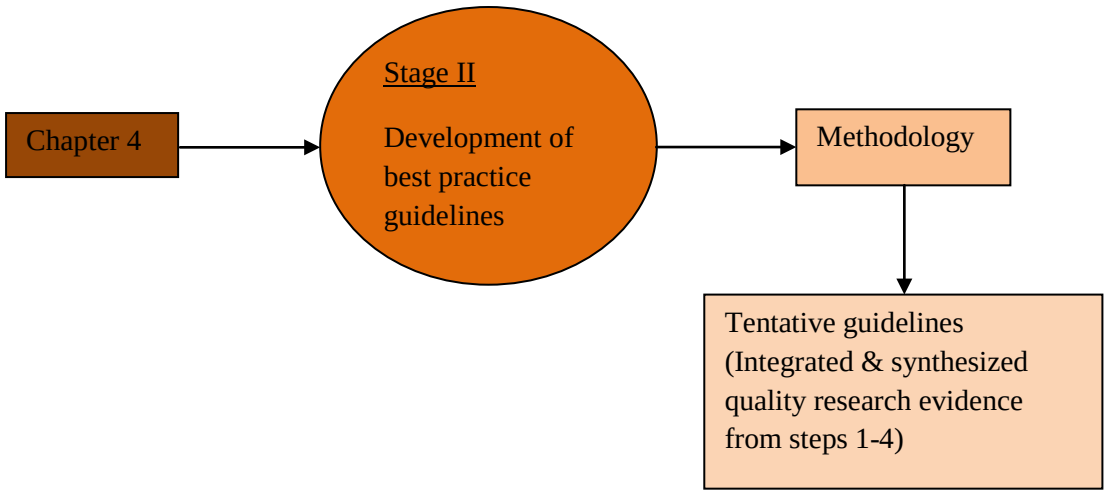


Figure 4.1 A summary of the presentation of chapter 4

4.2 RESEARCH METHODS

In this stage **(Stage II)** of the study, the tentative best practice guidelines for intensive care nurses on EOL care were developed. To achieve this, conclusions drawn from stage 1 (steps 1-4) were synthesised and integrated to provide evidence for the development of BPG. Logical reasoning was applied so as to develop best practice guidelines.

4.2.1 Logical Reasoning

Logical reasoning is the processing and organising of ideas in order to reach a conclusion (Burns & Grove, 2007:16). Through reasoning, people are able to make sense of both their thoughts and experience. Each part of an argument is linked to reach a logical conclusion. Once the evidence and its suitability to answer the clinical questions have been examined, the evidence needs to be turned into recommendations (National Institute for Clinical Excellence, 2005). Since the science of logic includes inductive and deductive reasoning (Burns & Grove, 2007), these two types of logical reasoning were applied in this stage.

4.2.1.1 Inductive reasoning

Inductive reasoning moves from the specific to the general. In this case, particular instances are observed and then combined into a larger whole or a general statement (Burns & Grove, 2007:16). This included grouping of all similar conclusions drawn from stage I of the study (steps 1-4).

4.2.1.2 Deductive reasoning

Deductive reasoning on the other hand moves from the general to the specific or from a general premise to a particular conclusion (Burns & Grove, 2007:17). This involved the development of recommendations from the integrated and synthesised conclusions drawn from stage I of the study (steps 1-4).

4.3 DEVELOPMENT OF BEST PRACTICE GUIDELINES

Development of best practice guidelines was carried out following the strategies provided in literature (McSherry, Simmons & Abott, 2002; Rosen & Proctor, 2003; National Institute for

Clinical Excellence, 2005; Bryant & Pace, 2009). At the initial phase, logical reasoning was applied. The two types of logical reasoning were applied in this stage. During inductive reasoning grouping of all similar conclusions drawn from stage I of the study (steps 1-4) was done. This mainly occurred during integration and synthesis level of the best practice guideline development. On the other hand, deductive reasoning involved the development of recommendations from the integrated and synthesised conclusions drawn from stage I of the study (steps 1-4).

4.3.1 Integration and synthesis of conclusions and development of best practice guidelines

To begin with, integration and synthesis involved clustering together similar conclusions drawn from steps 1-4 to form a new picture by means of inductive reasoning (refer to **table 4.2**). Thereafter, deductive reasoning was utilized while developing statements in the form of recommendations. The integrated and synthesised conclusions provided facts to support the recommendations within the best practice guidelines. From the conclusions drawn, the researcher realized that some conclusions dealt with a common aspect hence the relations led to the division of these conclusions into three categories. These included conclusions related to communication, caring and negative aspects impacting on EOL care.

Following which, each of the developed recommendations was categorised according to its strength of evidence as classified by McSherry et al. (2002:11) (Refer to **table 4.1**). Guideline recommendations were classified according to the strength of the supporting evidence, which was assessed from the design of each study (National Institute for Clinical Excellence, 2005). Finally, an elaboration of the integrated and synthesised conclusions was supported by a detailed discussion of evidence.

Table 4.1 Classification of the strengths of evidence (McSherry et al., 2002:11)

Class	Strength of evidence
I	Strong evidence from at least one systematic review of multiple well-designed randomised controlled trials
II	Strong evidence from at least one properly designed randomised controlled trial of appropriate size
III	Evidence from well-designed trials without randomisation, single group pre-post, cohort, time series or matched case-control studies
IV	Evidence from well-designed non-experimental studies from more than one centre or research group
V	Opinions of respected authorities based on clinical evidence, descriptive studies or reports of expert committees

To portray a picture of conclusions from the evidence and before commencing integration and synthesis including recommendation development, an outline of conclusions drawn from step 1-4 is presented in the following section.

4.3.2 An outline of conclusions drawn from step 1 to step 4 (stage I)

4.3.2.1 Step 1: systematic review

Factors that enable EOL care or good death in the ICU and supportive behaviours towards quality EOL care that helped nurses to move toward comfort care included consensus among patients, patients' families and staff about the direction of medical therapy, exhausting treatment options and patients' lack of responses to aggressive medical interventions. In addition, providing a dignified death, not allowing the patient to be alone while dying, managing patient's pain and discomfort, knowing and then following through patient's wishes for EOL care, promoting earlier cessation of treatment and not initiating aggressive treatment at all, communicating effectively as a health care team, providing clear, direct and consistent information, continuity in nursing care, nurses' knowledge, nurses' competence, cooperation and educational initiatives for professionals and public were also suggested as some of the factors that improve quality of EOL care and promote a good death in the ICU.

The barriers identified included: misunderstanding of the illness by patient's family, family discord and shifting medical care decisions, providing futile care, limited nursing time, constraints, rigid staffing patterns, communication challenges, treatment decisions that were based on physician rather than patient needs, behaviours of families that remove nurses from

caring for patients such as frequent phone calls, behaviours that prolong patient' suffering or pain, physician's disagreement about the plan of care and lack of nurses' knowledge, skills and sense of cultural competency to provide quality EOL care.

Nurses' experiences of EOL care were also reported. Doing one's utmost, was dominated by the nurses' endeavour to provide dignified EOL care. It was considered tragic when a patient died without the presence of a family member and in such cases, nurses provided warm and compassionate care to the unaccompanied patients by never leaving them alone during the dying process.

Frustration with physicians and communication problems between physicians, nurses, patients and families was also expressed by nurses as contributors to their dissatisfaction. Nurses reported that physician authority in discussion and decision making was acknowledged and that even though providing information to the patients is something that nurses know they should do, they expressed reluctance to do so fearing reprimand by the physician. Nurses expressed the need for physicians to speak frankly with family members so as to promote family satisfaction and avoid family distress during EOL care.

During their caring process, nurses also stated that they may lack knowledge and skills in EOL care, find caring for dying patients and their families stressful and lack support to provide this care. Apart from this, participants reported the importance of care of relatives, religious support, ensuring patient's symptom control and comfort measures (such as pain control, hygiene, positioning and suctioning) family being more often involved in decision making and encouraged to be involved in the care of their loved one as these contributed partly to their satisfaction of care rendered to their loved one.

On the other hand, family members described their experiences and feelings when a loved one was receiving EOL care in the ICU. They reported that their dying loved one's serious condition and his or her dependence on the medical-technical equipment were experienced as more frightening than the equipment as such. Being confronted with the threat of loss, they maintained a vigil while at the same time trusting the care provided to their loved one and

trying to adapt/understand the whole situation. The family reported the need for privacy and togetherness so as to experience reconciliation. It was also reported that adequate communication, good decision making, and respect and compassion shown to both the dying patient and their family were key determinants to family satisfaction.

In addition, family members wanted to be informed of any changes, have an opportunity to discuss treatment and have questions answered by nurses and doctors, have the same group of nurses provide care for consistency, have one hospital staff member act as the family contact so as to avoid confusion, have time with the patient in preparation for death and eventually have flexible visitation policies which maximize access between family members, their dying loved one and health care professionals.

The findings on discussion and decision making during EOL care revealed that nurses perceived physician as the rightful initiator of discussion as well as the final decision maker. Nevertheless, a European study showed that most nurses were involved to a large extent in EOL decisions, but not as initiating the discussion and once a decision was made there was a sense of agreement between the health care team. It was also reported that senior nurses are often actively involved in EOL decisions than junior nurses because senior nurses have more experience and are naturally likely to be involved. Less involvement was associated with cultural differences in different countries. Of most importance, nurses reported their role in supporting the family and being a patient advocate during this tough moment. Above all, the results indicated that nurses should be more involved in family-physician communication/decisions and contribute to building a team for family support.

Despite well documented strategies to prepare families for EOL, the families' perceptions revealed ineffective and unclear communication strategy. In most cases, it was shown that relatives want a more active role in EOL discussion and decision making in order to communicate the patient's wishes. However, many considered their role to be unclear, and few of them experienced shared decision making. In addition, EOL decisions were discussed with the family in some of the cases and in some, the families were more often told than asked about EOL decisions. Discussions did not occur with families in many cases because

the patient was unresponsive to maximal therapy or because the physician believed that the family would not understand. Family-physician disagreements that arose were significantly associated with less family satisfaction with decision making and decreased feelings of support during the process. Family members felt more support and were more satisfied with the decision making process when spirituality was addressed during family meetings.

4.3.2.2 Step 2: Experiences of family members on end-of-life care

Communication and receiving information was one of the important need raised by all family participants. Even though they all needed to be given information regarding their critically ill family members, they were not satisfied about how this was done, as they felt they were not given all the necessary information they needed. Due to inadequate information, the families felt like they were left in darkness most of the time. In order to obtain answers to their questions, they had to ask. They needed a daily report about the patient's status but this was not available. It was frustrating when they wanted to ask, the doctors were busy and the nurses would not or did not want to divulge the information. The families had to wait for the doctor and sometimes they had to go home without getting the information they needed to know.

It was also confusing when the families found different staff members caring for the patient giving contradicting information. This not only raised some mistrust but also portrayed a lack of unity and communication among the staff. Directions as to what to expect and what to do from the time when a decision of "not for resuscitation" was made till death was not available for the families. In such instances, families were left to wonder what to do and how to do things while they waited for the death to occur. It is important for critical care units to ensure that families of patients who die in the ICU are provided with consistent information, attention, and access to both the patient and health care professionals.

Another significant issue that emerged from the interviews was concerned with emotional support. All families expressed emotional disturbances and expressed the need for support at such a difficult time in their lives. Hope was common in all families and, despite being told about their relative's poor prognosis, they still had hope that a miracle would happen and that

the patient would get well. This could indicate that the families had not or had to come to terms with the situation gradually. In spite of the outcome, the families wanted to be reassured that their loved ones would be kept as comfortable as possible in terms of pain management and hygiene. They all acknowledged that their family members appeared clean and comfortable. One concern raised was noise from the staff as families thought this could have caused discomfort to ICU patients as much as it was to them.

The reception to ICU was considered by the majority as inadequate. Patients' families expected hospitality and empathy but this was not provided by all the nurses. In order to decrease their stress level, families mentioned that they needed someone to talk to as well as to encourage them. Ideally, nurses should have been available for these families to provide emotional support and information till the end. However, it was reported that the nurses were not always in the patients' rooms. Frequently, when the nurse came to the room, she took a few minutes to attend to the patient and left again and (when she could talk to the family) this would be done hastily. This behaviour from the nurses made families feel unwanted. This raises the need for the ICU team to continuously prepare and support the families throughout the time the patient is in the ICU so as to reduce the level of stress and uncertainties. It also implies that nurses should be assisted to develop and refine their communication and interpersonal skills and given support for their interactions with family members.

The other major finding from the interviews was the lack of family involvement in decision making and direct patient care. All families wanted to be involved in the decision making process regarding the care of their loved. Unfortunately, this was not done as they were often told about the decisions that had already been made rather than being involved in the decision making process. The families felt they should be included in the whole process as they are in a better position to know the patient's preferences than the ICU team. They also felt that they were in a position to advocate for the patient. Mostly, they felt as if the decisions came from the physician and neither the nurse nor the family could object since, once the decision was made, the care was steered in that direction.

Participants wished to be involved in the direct care of their loved one. Although this was their wish, the settings where the research was done do not allow families to participate in patient care in the ICU. The reason behind this could be that nurses are afraid that family members can make mistakes that could be harmful to the patient and they, as nurses could be held accountable. Nevertheless, families expressed the need for supervision and nurses' presence if they were able to assist with caring for the patient so that they can know what to do and what not to do. Involvement in direct patient care could be of importance to the families as it will allow them to be close to the patient during the last moments and it might enhance their satisfaction towards the care and comfort measures offered to their dying relative.

A further issue that emerged from the interviews is the need to access the patient at any time. All families except two expressed the need to be with their ill family member whenever they wished. Visiting time for families of patients at EOL is always open in these settings. It appeared that some families were not informed about this benefit. To them waiting from one visiting time to the next one was too much as they kept thinking about what could be happening when they were away from the patient's bedside. Being at the hospital helped to reassure them as they were able to see the patient still alive. It could be necessary for ICU team to give full information and to encourage visiting and its importance and what they should do as this could encourage even those who never wanted open visits to visit more often.

Finally, spirituality was another aspect that emerged from the interviews with the families. All families valued religion and the support from their religious leader as a form of support during this difficult time. Even though they did not receive such a support from the ICU team, they all prayed for the patient and, at the same time they approached their spiritual leader to encourage them and to pray for the patient. Spirituality was viewed as a source of hope to recovery, and when recovery was not possible, a way of making peace and allowing the patient to die peacefully in a dignified manner.

4.3.2.3 Step 3: Experiences of critically ill patients on comfort care

One of the major finding from the interviews in this study is the patients' desire to be cared for by someone who would feel and understand what they are going through while admitted in the ICU. Although compassion including psychological care or reassurance was not valued all the time by the nurses, it meant a lot to the patients. Nurses' compassion and reassurance meant that the nurses cared and contributed to their psychological satisfaction and decreased anxiety.

While the majority of the patients reported that their personal hygiene was maintained, patients also wanted their dignity to be upheld by the nurses. In addition, inadequate pain management appeared to be the most common problem for the patients interviewed in this study and this reflects how uncomfortable the majority of the patients were. To add to their discomfort, it was reported that the ICU was too noisy and this contributed to disturbances in sleep and relaxation.

Another significant finding that emerged from the patient participants' interviews was communication. The majority of the patient participants were not happy with communication between them and the nurses. Even though they were not able to respond or talk, most of them could hear but seemingly their non-responsiveness might have let to decreased amount of communication from the nurses. It felt like intrusion of privacy when the nurses went ahead with the interventions (as it happened to some patients) without explaining the procedure or informing the patient about what was about to be done beforehand. It was also evident that patients desired to receive information in a language they could understand and to be oriented not only about interventions but also about what was happening in their surroundings.

In addition, though technology contributes to caring, it was found that some nurses concentrated much on the machines and equipment with less attention directed to the patient. When lack of attention and communication occurred, patients felt neglected and they appeared just like an object of care and not human beings. It is thus thought that communication with sedated or unconscious patients in ICUs should not be viewed as only an

interactive process. Rather, it should be perceived as a means of providing the information and support that such patients need hence reduced amount of stress.

Trusting the nurses appeared as another important theme from the patient participant interviews. While some patients trusted the nurses with their personal information and their care, others had lost faith in them. The loss of trust in the nurses was mainly due to the way nurses treated the patients. Lack of respect and unprofessional behaviour towards the patient contributed to a loss of trust in the caring nurse. In addition, as mentioned by some of the participants, the nurses' lack of knowledge and inability to communicate and share information to the patient were also regarded as sources of mistrust between the nurse and the patient.

Of importance to the patient participants also was presence. The presence of a nurse at the patient's bedside was valued by all the study participants as a source of relief, safety and security. Even though it may not be practical for the nurse to be at the patient's bedside throughout, the nurse should make an effort to attend and respond to the patient's needs on a regular basis. This will serve to alleviate worries and anxieties that were found to be common in study participants in this study.

The presence of family though not valued by two of the patients was considered to be of importance by most of the participants. Those who did not want family to be around believed they were comfortable in the hands of the healthcare providers. They perceived the presence of family and friends as a threat to their lives because they did not want families to know about some things going on in their lives.

Those who mentioned that the presence of the family is important wanted more time with them outside visiting hours as they did not only get encouragement from them but it also made them feel safe. While some wished the family could participate in their care, some wanted the family to be involved in the decision making process as this was the only way their preferences could be known to the health care personnel especially during the time they were critically ill and not able to communicate.

Finally, religion and spirituality which arose as one of the major findings in this study was valued by all the patients. In most cases, patients prayed for themselves in their beds. Prayers gave them solace, hope for recovery and drew them closer to God. While most of them received spiritual support from the family and friends, this was seldom offered by the nurses or ICU team except in one occasion where a nurse prayed with one of the patients.

On the other hand, patients also valued spiritual support from religious leaders. Whereas some of them wanted such a support only from the spiritual leaders known to them, others did not mind having any spiritual leader coming to pray for them. Bearing in mind that patients came from culturally diverse population with different religious backgrounds, those who did not want prayers from unknown people believed that prayer is about believing what the bishop/father/priest/pastor says and where he comes from. This division about who should offer the spiritual care showed that ICU team should bear in mind about the patients' religious backgrounds and respect their preferences if they have to organize or allow spiritual leaders to offer such a care in the ICU.

4.3.2.4 Step 4: Intensive care nurses' experiences of end-of-life care

One of the major themes that arose was challenges. Nurses reported that it is challenging to care for the patients at end of life including their families and this was expressed in various ways. First, nurses found it challenging psychologically and emotionally especially when they had to care for younger patients or patients that had been in the unit for a longer period. The difficulty of letting go was associated with the bond that had developed between the patient and the family. As humans, nurses also felt emotionally disturbed expressed as painful, heartbreaking and draining among others when they saw such patients suffering and slowly dying.

In terms of communication with families, the nurses had difficulties concerning whether to talk to them or not about the patient's prognosis and progress. While it was thought that talking could lead to confusion and misinformation, nurses also thought that it was tricky because the family could use their words to put them in a 'corner' or trouble. In most cases, they would refer the family to the doctor for any explanations needed. The other reason given

as to why nurses were reluctant to talk is because it was not in their scope of practice to do so.

On the other hand, dealing with families in denial was also reported to be a challenge. Whereas a few regarded such families as troublesome, the majority tried to accommodate them as they understood that it was part of the stages of grieving and that families needed time to come to terms with the news. Despite the need to end patient's suffering, it was not easy to initiate limitation of treatment especially in patients who had been in the unit longer and had developed relationships with the nurses. A few nurses generally found it totally difficult to start limiting life sustaining therapies such as inotropes. The reason behind this is that such nurses did not want the patient to die under their care. This meant unnecessarily keeping the patient alive and prolonging suffering which was regarded by the majority as not adding value to the patient at all. On the other hand, nurses expressed desperation when the doctor's orders were not clear. Having to continue some activities such as blood gas analysis and continuous monitoring despite of little hope for survival was frustrating.

The other challenge experienced by the nurses was about who to contact when they had to move from curative to palliative care. Even though they normally have at least two or three contact persons on the patient's chart, it sometimes became hard for them to decide who to call. In such cases, some nurses suggested that the family should appoint one family member to act as the family representative. This person should be the one to be contacted in all situations if need be and he should be the one to liaise with the rest of the family.

Of much significance from the focus groups also was end of life discussions and decision making. When asked whether they are involved in end of life discussion and decision making process, nurses reported that they are not. Rather, the doctors make decisions and thereafter, they come and ask them of their opinions. In addition, it was found that a few most experienced nurses shared their opinions concerning the decisions that had already been made. In most cases, nurses agreed with decisions made without arguing. This was because of the fact that doctors do not listen to them nor value their inputs.

Nevertheless, nurses mentioned that being a team, they would like to be involved in the discussion and decision making process. Involvement would ensure that they can also share their ideas concerning the goal of care considering that they are the ones with the patient and family much longer time than any other staff. Despite of this, a few nurses did not want to be involved because they are not God to determine someone's life span. They believed that miracles do happen and sometimes even if doctors say the patient may not survive, some do come up.

The other major theme that came up was support for patients. This form of support implied to all those activities that would ensure patient's comfort in the dying process. As religious and spiritual support has been associated with a peaceful death, this form of support was supported by all nurse participants. Whereas it was supported by all, not all of them were willing to offer this support. Although some of them were comfortable praying for the patients having consulted the families, a few mentioned that it was not their duty. In most cases, it was preferred to either ask families to bring their own spiritual leaders, organize for those patients who did not have families or arrange for some support organizations. Because it was not always easy to get hold of spiritual leaders for those patients who did not have any, nurses suggested that the hospital should organize a specialized person on standby to be conducted when need be.

Without neglecting and until nature takes its course, nurses reported that they do offer basic nursing care to patients at end of life just like any other patient with a chance of survival. Above all, nurses mentioned that it is their duty to assess and minimize suffering by keeping the patient pain free all the time. To achieve this, nurses said they administer analgesics and sedatives as prescribed or when needed despite its double effect that could result to respiratory depression. Where not available, patient advocacy for prescription of these medications as reported comes in.

Additionally, family presence and participation in direct patient care was regarded as the other form of patient support. Families' presence was considered as not only a way to ensure that the patient is not alone during the dying process but it also acted as a way of gradually

preparing the families to the imminent lose and a source of satisfaction with end of life care. Although nurses did not encourage families to participate in direct care, they reported that they always allow them to participate if they raise their desire to take part. The reason as to why they did not often ask families to take part was because of the fear that families may make mistakes that could risk their job and the institution. On top of these, nurses' presence with the patient was also viewed as important to the patient. In spite of this, not all nurses were able to do so because of nurses' shortage and lack of time as they were expected to conduct other activities out of the patient's room.

Moreover, it was noted that the noise level in the ICU is higher. Lowering the noise level of especially from the staff would ensure a quite surrounding hence a source of comfort to the patient. Apart from this, the minority of the participants suggested the need for a private room for the dying patients, families and other patients' privacy. Those who were against patients being taken to a private room mentioned that it was because the family would feel that the patient is being deserted and disowned.

Support for families appeared as the other most significant finding. This type of support involves all the actions that could make the families feel better even if it is emotionally draining and difficult to lose a close relative. Given the fact that nurses are mostly busy, they raised a need to have specialized support persons such as a spiritual leader, social worker, psychologist or support organizations to assist in comforting and reassuring the families. Bearing in mind the peoples' cultural differences in the present society, it was mentioned that patients' and families' wishes including practices of rituals should be respected. Even though this was the case, these practices would not always be valued especially where it could result in negative effects to other patients or the hospital.

Furthermore, open visitation was advocated by all nurse participants. In terms of accompanying the family when the patient's death neared, a few nurses reported that they would ask the family if they would like them to stay in the room for support. Due to limited time, most of them said it was not possible to stay with the family in the room because they had other assignments to carry out. Nonetheless, they were willing to make them as

comfortable as possible before leaving them in the room by offering them whatever they needed such as tea, chairs, shock mixture or water among others.

Through experience, nurses had noted that often families do not receive early preparation concerning the patient's prognosis. It only came as a shock at the end when they were told that the patient may never survive. The nurse participants suggested that the doctors should start informative meetings from the first day of patient's admission so as to prepare the family of what to expect. At the same time, it was reported that nurses do not attend while such meetings are being conducted. The need to be present in the meeting was stressed as this could ensure that the nurse knows what is going on hence the ability to support the family in terms of clarifying information during the meeting or afterwards at the bedside.

Lastly, support for nurses emerged as the other major theme. It was clear that nurses face a lot of challenges while caring for patients at end-of-life and the families of such patients. Some of the challenges experienced included: psychological and emotional distress, lack of strategies of dealing with families, insufficient knowledge and experience in end of life care including lack of support from the institution. To overcome these challenges, nurses mentioned that they also need to be cared for and supported in order to be able to holistically care for the patients and their families. In the list, nurses mentioned the importance of debriefing sessions, training, team work, shift changes and time to adjust in between a patient's death and a new admission as ways that could support and enable them to cope.

For clarity, refer to **appendix Z** for common themes or categories that were pooled from steps 1-4. These themes assisted during synthesis and integration as the researcher was able to cluster together similar responses from the four sources of evidence. A complete representation of the integration and synthesis of the conclusions drawn from step 1-4 and the development of the recommendations is provided in the following section (**table 4.2**).

Table 4.2 Integration and synthesis of conclusions from step 1-4 and recommendations

Category of conclusion	Integrated and synthesised conclusion	Recommendation	Strength of evidence
COMMUNICATION	Patients felt neglected and appeared just like objects of care and not human beings when decreased attention and communication occurred as nurses concentrated much on the machines and equipment or went ahead without explaining the procedures	While managing medical and technological challenges, a nurse should offer explanations, interact and practice verbal/nonverbal communication even to the unconscious and/or critically ill dying patient to uphold humanity	V
	Patients and families desired to receive information in a language they could understand	Since South Africa is a culturally diverse nation, a nurse should find out about a patient's and families' preferred language of communication and ensure that there is no language barrier during nursing care delivery which may lead to miscommunication and compromise patient/family-nurse relationships	IV
	Having properly completed advance directives relating EOL care can reduce confusion about the goals of care hence there is a need of knowing and then following through patient's and families' wishes for EOL care	In order to reduce misunderstandings about the goal(s) of care, obtain a living will from the patient early in the care or inquire about existence of a living will and respect the patient's wishes for EOL care	IV
	In cases where the patients could not communicate, they preferred their families to be involved in the decision making process as a way of making their wishes known to the doctors and nurses. On the other hand, families did not only want to be told about made decisions but they also wanted a more active role in EOL discussions and decision making in order to communicate the patient's wishes	If a patient has a decision making capacity, he or she should be involved in every decision concerning his/her treatment. If the patient has no decision making capacity, discussions about EOL care should be held with the family as a way of communicating the patient's wishes and honouring the patient's choices	III

	Without having to ask, families wanted to have a doctor/nurse always available to offer adequate patient's progress report on a daily basis and to answer any questions they might have. Similarly, nurses mentioned that doctors should start informative meetings from the first day of patient's admission so as to prepare the family of what to expect	Prepare the families for what to expect. The doctor or a nurse should always be available to clearly communicate and offer a daily patient progress report from the first day of admission despite the prognosis	IV
	Families found information confusing when they found different doctors and nurses caring for the patient. In such cases, families wanted same group of nurses and doctors to provide care for consistency or have either one nurse or doctor to act as family contact so as to avoid contradicting information and confusion	Have either one nurse or doctor to act as the family contact person. If not possible, there should be continuity of patient care and nurses and doctors should be as consistent as possible so as to avoid conflicting information and confusion	IV
	Families wanted directions as to what to expect and what to do from the time when a decision of "not for resuscitation" was made until death	Although it may not be easy to predict what will happen, the doctor should inform the family of "what to expect" once a not for resuscitation order has been given. Continue answering questions, offering information of what to expect regarding changes in the patient's status and support family members even after the patient's death	II
	Frustration and communication problems between doctors, nurses, patients and families was expressed by nurses as contributors to their dissatisfaction	Encourage collegiality. Carry out effective communication with mutual respect between nurses, patient, families and the treating doctor for quality EOL care	IV
	Nurses wanted one family member to act as contact person so as to promote clearer communication process and prevent disturbances from frequent phone calls from other family members and friends	Have one family member as a designated contact person and provide information about the patient to the family on a regular basis to reduce the number of incoming calls handled by nurses	II

	A need was raised for nurses to be more involved in doctor-family communication/discussion/decisions and contribute to building a team for family support.	Involve nurses in the doctor family meetings including EOL discussion and decision making processes	IV
	Nurses expressed desperation when the doctors' documentation and orders were not clear relating EOL care, for example where one doctor would say there is no escalation of treatment and another doctor then prescribes an additional treatment (e.g. give colloid bolus). Another example given by nurses that was frustrating was having to continue certain interventions such as blood gas analysis and hourly vital signs monitoring despite of little hope for survival	When the primary goal of care has shifted from cure to comfort care, it should be made known by the treating doctor to the nurses verbally and through clear written documentation on the patient's chart. Futile care should be avoided by an open discussion and agreement on what "no escalation of care" means between the treating doctors and nurses– to reduce frustration for nurses which may affect patient/family care during EOL	IV
CARING **Basic physical caring**	Majority of the patients were in pain that was inadequately managed while admitted in the ICU. Nurses expressed the need of advocating and ensuring patient's symptom control and comfort measures (such as pain control, hygiene, positioning and endotracheal suctioning)	Assess for pain and discomfort and manage as necessary. Where orders are not in place, advocate for the patient to receive drugs for symptom relief. Continue interventions to ensure comfort throughout EOL care	IV
	Families wanted to be reassured that their loved ones would be kept as comfortable as possible in terms of pain management and hygiene	Reassure families and emphasise the fact that the patient will be kept as comfortable as possible	IV
	Nurses mentioned that despite the prognosis, they always continue basic nursing care until the patient dies	Despite the poor prognosis, a nurse should not withhold basic nursing care during EOL care	IV
	As much as families wished to participate in direct patient care, nurses also recognized the importance of family being allowed and encouraged to be involved in direct care of their loved one under supervision	Encourage and allow families if they are comfortable to take part in direct care of the patient; which can be done under supervision	II
Emotional caring	Compassion shown to both the dying patient and their family were key determinants to satisfaction and reduced	The nurse/doctor should show empathy to both the family and the patient, listen to the	IV

	anxiety. Families reported that having a patient at EOL is emotionally challenging and stressful. They wanted hospitality, empathy, someone to talk to, to encourage them, a shoulder to lean on and nurses to generally be in their shoes in order to decrease their stress level.	family attentively, address concerns and provide frequent contact and presence	
Spiritual caring	Patients and families valued spiritual support from their religious leader. Spirituality was viewed as a source of hope to recovery, and when recovery was not possible, a way of making peace and allowing the patient to die peacefully in a dignified manner.	As per the patient's/family's requests or wishes, (if relevant) allow their own religious leaders access to the unit to provide spiritual support	III
	Nurses valued spiritual support for both families and patients. Those who were willing provided the support, otherwise families were allowed to pray with and for the patient or bring in a religious leader	The nurse should assess the need for spiritual support and discuss with the patient/family the possibility of offering such support if comfortable. If not, liaise with the family and organize for a religious leader to come and provide support	IV
	It was not always easy to get hold of spiritual leaders for those patients who did not have families around or any spiritual leader known to them, due to this, nurses suggested that the hospital should organize a specialized person on standby to be contacted when need be	The hospital should make a list of available religious leaders/appoint a religious leader(s) on standby to offer spiritual support when needed, especially for those patients/families that need the support but do not have any religious leader	III
Presencing	The nurse's and families' presence at the patient's bedside was perceived as a source of relief, encouragement, safety and security by patients. To ensure a dignified death, the patient should not be allowed to be alone while dying	Encourage families to stay with the patient whilst dying. Where families are (not) around, nurses should be present by the dying patient's bedside so that the patient does not die alone.	IV
	Apart from nurses, families expressed the importance of flexible visitation policies as they were more relaxed while with the patient as compared to being away from the unit.	Provide, and discuss with the families flexible visitation policies	II

	Families felt emotionally overwhelmed, frightened and unwanted when nurses were not always in the patients' rooms or when they came to the room, took a few minutes to attend to the patient and left again or talk to them hastily.	Explain to the family why the nurse is leaving the room. In spite of various activities that need to be done outside the patient's room, nurses should create time to be with the family at the bedside as a form of support. The nurse should inform the family why he/she is leaving the room, which could decrease stress	IV
	Families did not know what to do while they were in the unconscious' patient's room alone	Teach the patient's family members how to act around a dying patient, encourage them to touch and speak to the patient	II
Support	Nurses stated that they may lack knowledge and skills in EOL care, and educational or training services are needed to improve quality of EOL for both the patient and the family	Offer continuous education on skills, knowledge and attitude on how to support patients and families at EOL especially to the newly qualified, inexperienced and junior nurses	III
	Nurses raised the need to support each other as colleagues as lack of cooperation and team work was associated with stress and burn out	Encourage collegiality and collaboration so as to work towards the same goal for the best EOL care	IV
	Nurses acknowledged the challenges they have and inability to achieve optimum EOL care. Due to this, nurses suggested incorporation of specialized multidisciplinary team including social worker, spiritual leader, psychologist so as to meet the patient's and families' specific needs	Discuss the availability of expert additional support services for a dying patient and grieving families. If required, organize for support from either a social worker, psychologist, or a religious leader	IV
	Nurses stated that they find caring for dying patients and their families psychologically and emotionally challenging and lack support such as debriefing	Assess emotional reactions of the staff while caring for the dying patient and institute support mechanisms such as debriefing sessions by a counsellor	IV
	In between the death and a new admission, nurses want a few hours to adjust/grieve	Allow nurses a few hours to grieve, recover and be able to move on after a patient's death and before a new admission since EOL care could be exhausting and draining	IV

	Because it is a stressful and emotionally draining situation (dealing with the dying patient and families), nurses want changes of shifts on a daily basis	As a nurse's coping strategy, let a group of nurses take turns caring for a dying patient by means of change of shifts on a daily basis	IV
	As they may not be able to cope, it was mentioned that recently bereaved staff should not be assigned such patients until they can cope with their own loses	Assess the ability of a nurse who has recently been bereaved in engaging in EOL care. Support those nurses who may not wish to engage in EOL care until they have coped with their own lose and have indicated their readiness	IV
Respect	Patients wanted their dignity to be always upheld by covering them, closing the curtains and windows so as not to expose their bodies to the public	To maintain patient's privacy, always keep the patient's body covered or screen the patient when conducting procedures that need bodily exposure	V
	Families expressed the need of privacy and time with the patient in preparation for death	As per their wish, allow the family time with the patient in private in preparation for death	II
	Minority of nurses suggested the need for a private room for the dying patients, families and other patients' privacy.	If possible, move or nurse the patient in a single room to promote confidentiality and privacy for the dying patient/family and to protect other patients in the unit from disturbing scenes	IV
	Nurses reported that patients' and families' wishes, culture, traditions including practices of rituals should be respected unless such practices would result in negative effects	Find out about patient's and families' wishes, culture and traditional practices and respect them when necessary	IV
NEGATIVE FACTORS IMPACTING ON CARING	Patients, families and nurses reported that there is high level of noise in the ICU	As much as possible, avoid stressful impulses and sensory disturbances by promoting decreased noise level and a peaceful and quiet ICU environment	IV
	Family discord and misunderstanding of the illness by patient's family was regarded as an obstacle to provision of quality EOL care	Clarify with family members their understanding of the patient's illness and treatment options, communicate effectively	II

		and if possible, have all family members together in a meeting for explanations and conflict resolutions	
	Limited nursing time, and staff shortages did not allow nurses to always accompany and support the dying patients and their families as they had to do other assignments in the unit	Relieve the nurse of all other responsibilities in order for him or her to have time to focus on caring for the dying patient and the family	IV
	It was not easy to initiate limitation of treatment especially in patients who had been in the unit longer and had developed relationships with the nurses. A few nurses generally found it totally difficult to start limiting life sustaining therapies such as inotropes. This meant prolonging suffering. In some instances, nurses did not agree with the doctors' decisions and they thought that life sustaining therapies had been prematurely limited. In such cases, nurses had hopes for recovery and they did continue intervening despite the orders	Working as a team, discussions should be held among nurses and doctors as a way of preparation towards moving from curative to palliative care. In order to deal with undue distress caused by moral and ethical issues, the rationale for decisions should be clearly understood by all parties and each individual should have a chance to express any concerns they might have regarding EOL care	V

Presentation of best practice guidelines included providing statements on what need to be done based on the conclusion drawn. As recommended by the National Institute for Clinical Excellence (2005), guideline recommendations should focus on what need to be done. In the following section, each of the BPG is provided including its strength of evidence and discussion of evidence.

4.4 BEST PRACTICE GUIDELINES ON END-OF-LIFE CARE FOR INTENSIVE CARE NURSES

Guidelines were developed with reference to the South African Nursing Scope of Practice (The South African nursing council, 2008) and are intended to be implemented and applied in consultation with the South African nursing council. This is due to the fact that the scope of guidelines is intended for South African intensive care nurses. Thereafter, the guidelines will be disseminated to the participating ICUs in a form of a summary document for its pilot testing and implementation before its widespread implementation. Due to the foreseen barriers and potential resource implications, recommendations have been made (in chapter 6) to the nursing management to consider such factors so as to facilitate application of these guidelines in the practice setting.

As indicated in literature, guidelines typically change, and because new evidence accumulates rapidly, guidelines should be reassessed for validity every three to five years to avoid obsolescence (Polit & Beck, 2008; Voisin, de la Varre, Whitener, et al., 2008). For this reason, the guidelines should be updated every five years.

The guidelines carry recommendations that focus on communication, different aspects of caring and negative factors impacting on EOL care. Although these BPG were developed with the purpose of informing intensive care nursing practice, as part of the caring team, contributions and participations of the multi-disciplinary team are encouraged for quality EOL care. Communication recommendations are intended to inform nursing practice, nursing management and nursing education regarding how to effectively communicate as health care team as well as instituting communication strategies in dealing with the dying patients and their families. Caring recommendations are intended to inform nursing practice, nursing

management and nursing education on how to promote quality care for patients and families at EOL and more so, the care needed by nurses in order for them to continue rendering holistic nursing care. These aspects of caring includes: basic physical caring, emotional caring, spiritual caring, presencing, support, and respect. Finally, negative factors impacting on caring at end-of-life recommendations have been provided to inform nursing practice, nursing management and nursing education on what need to be improved so as to ensure quality EOL care. For clarity, guidelines referring to families focus on individuals who provide support and with whom the patient has a significant relationship (Davidson, Powers & Hedayat et al., 2007; Fridh, Forsberg & Bergbom, 2009b:112).

Each of the recommendations from the three categories of conclusions, its strength of evidence and discussion of its evidence will be presented in the following section. Recommendations within the best practice guidelines have been presented in italics format in a box and where applicable, the conclusion that resulted in the recommendation has been elaborated upon (information provided in bullets format). To begin with, communication recommendations are presented first.

4.4.1 Communication recommendations

Recommendations related to communication at end-of-life are presented as follows:

1. *While managing medical and technological challenges, a nurse should offer explanations, interact and practice verbal/nonverbal communication even to the unconscious and/or critically ill dying patient to uphold humanity*– **Strength of evidence V**

- Giving explanation of procedures beforehand is perceived as reassuring resulting in less fear and insecurity (Hofhuis, Spronk & van Stel, et al., 2008).
- Communication is associated with satisfaction with care and psychological wellbeing (Nelson, Puntillo & Pronovost, et al., 2010:815)
- Inadequate communication results in increased levels of stress and anxiety (Alasad & Ahmad, 2005:356).

- Technical skills and medical equipment are perceived as necessary interventions, but nurses should be aware that patients sometimes perceive that increased attention to technical equipment decreases the patients' trust (Hofhuis, et al., 2008:310).
- Caring professionals need to balance the state-of-the-art technology with integrated and comprehensive care and harmonise the demands of subjectivity with objective signs (Almerud, Alapack, Fridlund, et al., 2008:136).

Discussion of evidence

Cornerstones in good nursing care are nurses' verbal communication and use of their hands, focusing on patients' object-subject bodies (Hov, Hedelin & Athlin, 2007a:339). To manage this, nurses must be trained in the 'difficult' conversation with seriously ill and dying patients. They should be trained holistic nursing care. Patients at the public sector tertiary academic hospitals mentioned that there were inadequate communication between them and nurses. In most cases, they felt like so that they can manage the medical and technical challenges without being hindered in executing they were being handled as objects since nurses concentrated much on the equipments than on them. They wanted nurses to talk to them because they could hear even though they couldn't respond verbally.

2. *Since South Africa is a culturally diverse nation, a nurse should find out about a patient's and families' preferred language of communication and ensure that there is no language barrier during nursing care delivery which may lead to miscommunication and compromise patient/family-nurse relationships* – **Strength of evidence IV**

- Language barrier during nursing care delivery may lead to miscommunication, dissatisfaction with care and compromise the patient/family-nurse relationship (Khathami, Kojan, & Aljumah, et al., 2010).

Discussion of evidence

Some of the critically ill patients and family members at the public sector tertiary academic hospitals expressed the need of ICU team to communicate to them in a language that they could understand. This mostly was raised by the foreign nationals who could not understand

local languages which are mostly used by staff. Language barrier was expressed as a source of confusion and worry.

3. *In order to reduce misunderstandings about the goal(s) of care, obtain a living will from the patient early in the care or inquire about existence of a living will and respect the patient's wishes for EOL care* – **Strength of evidence IV**

- Know and follow patient's wishes for EOL care (Beckstrand, Callister & Kirchhoff, 2006).
- Encourage persons with serious chronic illness to express their wishes as an advance directive or to make them known to their family and friends who can report them to the ICU staff (Cohen, Sprung, Sjokvist, et al., 2005).
- Ideally, an advance directive should be completed prior to the crisis of life threatening illness as it can be difficult to determine the patient's preference and the family may have difficulty deciding on the appropriate goal of the care of their family member (Crump, Schaffer & Schulte, 2010).

Discussion of evidence

Many of the obstacles such as family discord at end-of-life could be reduced through having a completed advanced directive that specifies the patient's preference for end of life treatment (Crump, et al., 2010:303). Elsewhere, nurses felt emotionally better about a patient's death when they were able to provide adequate comfort and honour the patient's last wishes or formal advanced directive (Badger, 2005a:520).

4. *If a patient has a decision making capacity, he or she should be involved in every decision concerning their treatment. If the patient has no decision making capacity, discussions about EOL care should be held with the family as a way of communicating the patient's wishes and honouring the patient's choices* – **Strength of evidence III**

- Since critically ill patients are commonly unable to think and participate in decisions as they may be unconscious, intubated, sedated and ventilated (Bell, 2007), discussion and

decisions about the patient's treatment should take place between the patient's family and the intensive care physicians and nurses (Efstathiou & Clifford, 2011).

Discussion of evidence

Most ICU patients are not competent to participate in EOL decisions; therefore a surrogate or family member is found to represent the patient (Cohen, et al., 2005:1217). In spite of this, the family is often told than asked about end of life decisions. As stated by Lind, Lorem, Nortvedt et al. (2011:1147), several family members, while presuming that the correct decision had been made, would still have preferred greater involvement in the decision making process. In addition, families with a loved one dying in ICU report more satisfaction with decision making process when involved in EOL decisions (Gries, Curtis, Wall, et al., 2008:707).

From the findings at the public sector tertiary academic hospitals, majority of the patients reported that their family know them better hence they would prefer their close family to be involved in decision making especially in the case where they cannot do so for themselves. On the other hand, families reported that they were often told about the decisions but not involved in the process. Their wish was to be involved so that they can share the patient's preferences about the care.

5. *Prepare the families for what to expect. The doctor or a nurse should always be available to clearly communicate and offer a daily patient progress report from the first day of admission despite the prognosis*– **Strength of evidence IV**

- Family meetings with the multi professional team should begin within 24 to 48 hours after ICU admission and should be repeated as dictated by the condition of the patient so as to deliver effective and regular information (Davidson, Powers, Hedeyat, et al., 2007:608).

Discussion of evidence

Meetings between the physicians and the family members should occur in a more timely fashion as this would give the family time to prepare and have quality time with the dying patient (Beckstrand, et al., 2006:40). Families at the public sector tertiary academic hospitals expressed the difficulty they found obtaining information they needed during admission of their relative. They reported that most of the time they were left in darkness and only knew about the poor prognosis at a later stage. Their desire was to receive patient's information and progress report on a daily basis without having to ask so as to know what to expect.

6. *Have either one nurse or doctor to act as the family contact person. If not possible, there should be continuity of patient care and nurses and doctors should be as consistent as possible so as to avoid conflicting information and confusion*- **Strength of evidence IV**

- Various and divergent information and opinions regarding the patient's condition may create further confusion (Beckstrand & Kirchhoff, 2005).

Discussion of evidence

From the families at the public sector tertiary academic hospital, meeting different staff at every shift and receiving different information about the patient was quite confusing. Families suggested that health care providers must communicate among each other and report same things. Having one individual at the hospital act as contact person for the family as well as having the same group of nurses working with the patient has been positively associated with reports of good care (Kjerulf, Regehr, Popova, et al., 2005:24). Moreover, ICU should develop creative means for ensuring that families of patients who die in the ICU are provided with consistent information.

7. *Although it may not be easy to predict what will happen, the doctor should inform the family of "what to expect" once a not for resuscitation order has been given. Continue answering questions, offering information of what to expect regarding changes in the patient's status and support family members even after the patient's death* – **Strength of evidence II**

- Transitioning to EOL care could take hours/days/weeks. Whatever the case, families should be prepared as to what to expect (Coombs et al., 2012).

Discussion of evidence

Some family members interviewed at the public sector tertiary academic hospital expressed the feelings of being left not knowing what to do from the time the decision was made even after death. As recommended by Beckstrand and Kirchoff (2005:402) supporting families should continue even after the patient's death.

8. *Encourage collegiality. Carry out effective communication with mutual respect between nurses, patient, families and the treating doctor for quality EOL care* – **strength of evidence IV**

Discussion of evidence

During the process of withdrawal or withholding of treatment, effective communication and cooperation as health care team should be carried out with mutual respect (Hov, Hedelin & Athlin, 2007b:210) as this would ultimately facilitate a good death because everyone could be working toward the same goal of care (Beckstrand, et al., 2006:42). Problems with communication among patients, families and physicians have previously been identified as contributors to the nurses' feelings of burnout (Zomorodi & Lynn, 2010a:95).

9. *Have one family member as a designated contact person and provide information about the patient to the family on a regular basis to reduce the number of incoming calls handled by nurses* - **strength of evidence II**

Discussion of evidence

One of the most intense obstacles to providing EOL care that has been reported is patients' family members and friends who continually call a nurse for an update on the patient's condition (Beckstrand & Kirchoff, 2005:397). The nurses in the public sector tertiary academic hospital expressed frustrations with frequent incoming phone calls from the

patients' families. Furthermore, these nurses at times were in situations whereby they did not know who to contact once a decision about end of life care had been made. To manage these phone call disturbances, recommendations as to having a designated family member be the representative for other family members in both providing and requesting information has been made (Crump, et al., 2010:303).

10. *Involve nurses in the doctor-family meetings including EOL discussion and decision making processes* – **strength of evidence IV**

Discussion of evidence

Even though nurses rarely participate in meetings between families and physicians as well as in discussion and decision making process, there is a need for nurses to engage more in end-of-life situations and contribute to building a team for family support (Lind et al., 2011). Intensive care nurses have usually built up a good relationship with the family members, resulting in insights and understandings that provide a knowledge base of the family members in their needs (Latour, Fulbrook & Albarran, 2009). This knowledge is essential when it comes to end-of-life discussions and decisions between nurses and physicians (McMillen, 2008). Nurses at the public sector tertiary academic hospitals are not involved in end of life discussion and decision making processes; neither do they attend family physician meetings. As part of the caring team, nurses reported that they would like to be involved in these processes so that they can also contribute in this caring process.

11. *When the primary goal of care has shifted from cure to comfort care, it should be made known by the treating doctor to the nurses verbally and through clear written documentation on the patient's chart. Futile care should be avoided by an open discussion and agreement on what "no escalation of care" means between the treating doctors and nurses– to reduce frustration for nurses which may affect patient/family care* **strength of evidence IV**

- There should be cessation of treatment that does not contribute to comfort and no initiation of aggressive treatment unless changes occur in goals of patient care (http://www.ICU+comfort+care+guidelines, 2008).

Discussion of evidence

In a study by Hov et al. (2007b:207), uncertainty existed when goals for patient's care were not set, were unknown, or when physicians gave conflicting messages. As was reported by nurses at the public sector tertiary academic hospitals, doctors' orders should be made clear and documented. Carrying out certain interventions that do not benefit the patient or initiation of new interventions should be avoided after the decision has been made. Similarly, several nurses in a study by Beckstrand et al. (2006:42) noted the frustration of continuing aggressive treatments when there was little hope of the patient's survival.

4.4.2 Caring recommendations

The following section provides recommendations related to caring at EOL. This has been divided into basic physical caring, emotional caring, spiritual caring, presencing, support and respect. To start with basic physical caring recommendations are presented as follows:

4.4.2.1 Basic physical caring

1. *Assess for pain and discomfort and manage as necessary. Where orders are not in place, advocate for the patient to receive drugs for symptom relief. Continue interventions to ensure comfort throughout EOL care* – **strength of evidence IV**

- Use standardized scoring systems based on physiologic variables and behavioural observations to provide an objective basis for pain management. Use medication such as opioid analgesic agents or sedative agents as prescribed for alleviation or prevention of pain, dyspnoea, and other distressing symptoms (Truog, Campbell, Curtis, et al., 2008).
- Continue other comfort measures such as suctioning if necessary, pressure area care, turning, and personal hygiene among others.

Discussion of evidence

Pain is one of most prevalent symptoms in intensive care as it is usually associated with procedures that patients dying in the ICU are subjected to as nurses aim to keep them

comfortable (Puntillo, Morris & Thompson, et al., 2004). The findings from the public sector tertiary academic hospitals also revealed that most patients were in pain that was not adequately managed. Due to this, sedative agents may be necessary during the patient's final hours to prevent discomfort and reduce pain or dyspnoea (Latour, et al., 2009). These authors including nurses interviewed at the public sector tertiary academic hospitals support continuation of other comfort measures such as suctioning, pressure care, turning and more so advocating for the patient to receive pain and comfort medication if not ordered.

2. *Reassure families and emphasise the fact that the patient will be kept as comfortable as possible* – **strength of evidence IV**

Discussion of evidence

Families want to be reassured that excellent care will continue to be provided with special attention to the comfort of the patient (Heyland, Rocker, O'Callaghan, et al., 2003; Kjerulf, et al., 2005; Fridh, Forsberg & Bergbom, 2009a). Most families interviewed at the public sector tertiary academic hospitals expressed the need of their patients to be kept as comfortable as possible even if they were dying.

3. *Despite the poor prognosis, a nurse should not withhold basic nursing care during care*– **strength of evidence IV**

- Like the patient with a potential to live, continue basic nursing care until the patient dies

Discussion of evidence

Nurses interviewed at the public sector tertiary academic hospitals reported that they continue nursing care in a dying patient until the last minute without giving up. In a study by Fridh et al. (2009a), nurses expressed the importance of considering EOL care just as equal in value to the care provided for patients with a good prognosis.

4. *Encourage and allow families if they are comfortable to take part in direct care of the patient; which can be done under supervision* – **Strength of evidence II**

Discussion of evidence

Having family members physically help care for a dying patient has been reported as one of the supportive behaviours at EOL care (Beckstrand & Kirchoff, 2005:399). Despite of this, unless relatives express an interest, very few are asked whether they would like to assist in care (such as turning or last offices) (Labram & Hughes, 2010:248). While this intimate involvement in care may allow relatives to come to terms with the imminent death of the patient and provide solace, they are likely to be reluctant to ask to help in administering the care if they perceive that it will not be permitted.

4.4.2.2 Emotional caring

Emotional caring recommendations during EOL are as follows:

5. *The nurse/doctor should show empathy to both the family and the patient, listen to the family attentively, address concerns and provide frequent contact and presence* – **strength of evidence IV**

Discussion of evidence

The abilities of the nurse to listen attentively, address concerns and provide frequent contact and presence have all been identified as ideal characteristics for providing EOL care in the ICU (Zomorodi & Lynn, 2010a:95). On the other hand, overall satisfaction with EOL care has been significantly associated with respect and compassion shown to the patient and family member (Heyland, et al., 2003:392). Of concern from the family members and patients interviewed at the public sector tertiary academic hospital was the need for someone to be in their shoes emotionally and to be present offering a shoulder to lean on. Apparently, not all nurses they encountered with during their care provided such forms of support.

4.4.2.3 Spiritual caring

Recommendations related to spiritual aspect of caring at EOL included:

6. *As per the patient's/family's requests or wishes, (if relevant) allow their own religious leaders access to the unit to provide spiritual support* – **strength of evidence III**

Discussion of evidence

Spirituality may provide a plat-form for family members to express themselves, feel comforted and cope with the death of their loved one (Gries, et al., 2008:709). Most patients interviewed at the public sector tertiary academic hospitals reported that they would trust prayers from spiritual leaders known to them. In most cases, families on the other hand organized and brought spiritual leaders known to them to pray for and with the patient.

7. *The nurse should assess the need for spiritual support and discuss with the patient/family the possibility of offering such support if comfortable. If not, liaise with the family and organize for a religious leader to come and provide support* – **strength of evidence IV**

Discussion of evidence

- It may be culturally more comfortable for staff and relatives to discuss religious support than engaging in very personal care of the patient (Labram & Hughes, 2010:248). In addition, nurses in the public sector tertiary academic hospitals who were willing to offer religious/spiritual support to the patient and family requested the family and the patient if it was fine for them to do so. Those who were not comfortable in offering the care assisted families and patients by arranging for a support organization or spiritual leader to come and attend to them.

8. *The hospital should make a list of available religious leaders/appoint a religious leader(s) on standby to offer spiritual support when needed, especially for those patients/families that need the support but do not have any religious leader*– **strength of evidence III**

Discussion of evidence

Nurses at the public sector tertiary academic hospital expressed the hardship they undergo when they have to look for a spiritual leader for those patients who do not have any. They therefore requested that the hospital should appoint a spiritual leader on standby to attend to such patients. As described by Hansen, Goodell, DeHaven et al. (2009:268), lack of spiritual support was a concern cited due to limited chaplaincy service at the medical centre.

4.4.2.4 Presencing

Recommendations associated with presencing at EOL care are provided in the following section as:

9. *Encourage families to stay with the patient whilst dying. Where families are (not) around, nurses should be present by the dying patient's bedside so that the patient does not die alone* – **strength of evidence IV**

- The needs and desires of families to be actively present in the final phases of their loved ones' lives should be respected (Gristina, Gaudio, Mazzon, et al. 2011).

Discussion of evidence

The findings from the public sector tertiary academic hospital revealed that patients and families would want to be accompanied at the bedside as this was seen as a source of relief, safety and security. Maintaining presence is one of the ways for nurses to help patients who face death, offer emotional support to the families and ensure the likelihood of them experiencing a 'good death' (Fridh, 2009a:238). Therefore nurses should stay with the patients so that the patients would not have to die alone (Badger, 2005a:517). On the other hand, families should be encouraged to stay with the dying patient (Beckstrand, et al., 2006:41) as this enables them to come to terms with the imminent death and make the most of the short time with patient (Fridh, et al., 2009b:115).

10. *Provide, and discuss with the families flexible visitation policies*– **strength of evidence II**

- In order to reduce the stress levels of families of ICU dying patients, families should be allowed to visit the patient any time (Davidson, et al., 2007:608).

Discussion of evidence

Even though open visitation is allowed to all families with patients at EOL, some of the family members from the public sector tertiary academic hospitals were not aware about this benefit. They expressed frustration, anxiety and stress having to wait from one visiting hour

to the next one and yet they could just walk into the unit any time they felt like seeing their patient. As documented, one of the supportive behaviours at EOL is providing a patient's family members with unlimited access to the patient (Beckstrand & Kirchoff, 2005:399).

11. *Explain to the family why the nurse is leaving the room. In spite of various activities that need to be done outside the patient's room, nurses should create time to be with the family at the bedside as a form of support. The nurse should inform the family why he/she is leaving the room, which could decrease stress* – **strength of evidence IV**

Discussion of evidence

Family members at the public sector tertiary academic hospitals felt emotionally overwhelmed, frightened and unwanted when nurses were not always in the patients' rooms or when they came to the room, took a few minutes to attend to the patient and left again or talk to them hastily. As described by Fridh et al. (2009b:116), being left alone by the staff members was described by families as distressing.

12. *Teach the patient's family members how to act around a dying patient, encourage them to touch and speak to the patient* – **strength of evidence II**

Discussion of evidence

In most cases, families at the public sector tertiary academic hospitals did not know what to do when they were at the patients' bedside as the patient could not talk nor respond to them. As one of the supportive behaviours, a nurse should teach patient's families on how to act around a dying patient **(**Beckstrand & Kirchoff, 2005:399). Nurses should explain the patient's condition, describe the ICU environment and medical devices as well as encourage them to touch and talk to the patient (Fridh, et al., 2009a:236).

4.4.2.5 Support

Recommendations related to support for patients, families and nurses include:

13. *Offer continuous education on skills, knowledge and attitude on how to support patients and families at EOL especially to the newly qualified, inexperienced and junior nurses* – **strength of evidence III**

Discussion of evidence

Nurses at the public sector tertiary academic hospital stated that they may not have experience and skills in caring for the dying patient and their families. The lack of adequate knowledge about EOL care becomes an obstacle to effective EOL care (Crump, et al., 2010:303). Providing specific EOL care skills, training and education for ICU staff and more so new nurses may help in the challenging transition from novice to skilled critical care nurse when helping dying patients and the patients' families (Hansen, et al., 2009:269).

14. *Encourage collegiality and collaboration so as to work towards the same goal for the best EOL care* – **strength of evidence IV**

Discussion of evidence

The findings from the nurses at the public sector tertiary academic hospitals revealed that there is lack of team work and cooperation during EOL care among nurses and other staff. Cooperation with nurse colleagues and physicians is essential in order to clarify goals to ensure best treatment and care (Hov, et al., 2007a:334).

15. *Discuss the availability of expert additional support services for a dying patient and grieving families. If required, organize for support from either a social worker, psychologist, or a religious leader* – **strength of evidence IV**

Discussion of evidence

Nurses interviewed at the public sector tertiary academic hospitals reported that they may not be able to meet the needs of all families and the dying patients due to time constraints. They therefore requested incorporation of specialized persons such as religious leaders, counsellors, psychologists, social workers or certain organizations to offer support to the

family throughout in the unit. Inadequate support services for grieving families has been identified as a barrier to optimal care whereas having access to other experts is seen as a way of improving end of life care (Bloomer, Tiruvoipati, Tsiripillis, et al., 2010:5) as such a team could focus on end-of-life care issues to enhance quality of care (Beckstrand, et al., 2006:42).

16. *Assess emotional reactions of the staff while caring for a dying patient and institute support mechanisms such as debriefing sessions by a counsellor* – **strength of evidence IV**

- After a patient dies, nurses may grieve and if grieve is concealed or suppressed it may lead to further stress which may undermine the effectiveness and quality of care offered (Calvin, Lindy & Clingon, 2009).

Discussion of evidence

While nurses at the public sector tertiary academic hospital experienced EOL care as emotionally and psychologically challenging, they reported that there is no form of support offered by the institutions. These nurses valued and needed someone to talk to after the patient died but instead, they ended up surviving with the emotional and psychological challenges encountered in the caring process. Due to emotional labour that accompanies end of life care, a recommendation for practice would be that support mechanisms such as debriefing should be in place for nurses and other members of multi-disciplinary team to discuss these issues when they occur (McMillen, 2008:257).

17. *Allow nurses a few hours to grieve, recover and be able to move on after a patient's death and before a new admission since EOL care could be exhausting and draining* – **strength of evidence IV**

Discussion of evidence

After death and before the next admission, nurses at the public sector tertiary academic hospitals reported that it was their wish to be given some time to adjust. This was due to the fact that caring for patients at EOL including their families and more so the occurrence of the death was draining and stressful. Nevertheless, as soon as the patient died, they were expected to just carry on and admit a new patient with their emotional burden as if nothing

had happened. As described by Fridh et al. (2009a:238), EOL care has been experienced as exhausting and nurses reported that afterwards they often felt drained and needed time to recover before they could care for new patients.

18. *As a nurse's coping strategy, let a group of nurses take turns caring for a dying patient by means of change of shifts on a daily basis* – **strength of evidence IV**

Discussion of evidence

Since the patient's death could occur any time ranging from a few hours to days later after a decision has been made, having the same nurse continuously caring for such patient was seen as a source of emotional stress by the nurses at the public sector tertiary academic hospitals. To prevent this form of stress, they expressed the need of change of shifts on a daily basis. Similarly, nurses in a study by Badger (2005b:67) mentioned that each and every one of the nurses should rotate through and take their turn caring for the dying patient and the families.

19. *Assess the ability of a nurse who has recently been bereaved in engaging in EOL care. Support those nurses who may not wish to engage in EOL care until they have coped with their own lose and have indicated their readiness* - **strength of evidence IV**

Discussion of evidence

As expressed by the nurses at the public sector tertiary academic hospitals, nurses who have just experienced the loss of a loved one should not be allocated to care for patients at end-of-life soon after the death of their close relative as they may not cope due to constant reminder of their own loses.

4.4.2.6 Respect

Recommendations that were developed related to respect to the patient and the family are:

20. *To maintain patient's privacy, always keep the patient's body covered or screen the patient when conducting procedures that need bodily exposure* - **strength of evidence IV**

Discussion of evidence

As was expressed by patients at the public sector tertiary academic hospitals, nurses and other health care providers should respect their bodies by covering and not exposing them to the public. It has also been mentioned that a patient's dignity is threatened when his or her intimate and private sides are divulged to irrelevant people (Hov, et al., 2007a:337).

21. *As per their wish, allow the family time with the patient in private in preparation for death* - **strength of evidence II**

Discussion of evidence

By providing privacy at the end-of-life, the staff make it possible for the family to have their own private space (Fridh, et al., 2009b:116). Moreover, it has been indicated that providing patient's family members with unlimited time alone with the patient even after death is one of the supportive behaviours at EOL (Beckstrand & Kirchoff, 2005:399). In addition, having the family have enough time with the patient before he or she dies has been positively associated with reports of good death (Kjerulf, et al., 2005:24).

22. *If possible, move or nurse the patient in a single room to promote confidentiality and privacy for the dying patient/family and to protect other patients in the unit from disturbing scenes* – **strength of evidence IV**

Discussion of evidence

As recommended by participants in a study by Beckstrand et al. (2006:41), patients should be moved to private rooms as it could be nice to have a comfortable, quiet, spacious room for those who are dying. Caring for dying patients in a multi-bed rooms has been experienced as frustrating because the nurse has to focus on the dying patient's family in addition to the well-being of fellow patients and their families (Fridh, et al., 2009a:238). For families, maintaining a vigil at a loved one's bedside is a very private experience and they do not want anyone to be able to observe or share in what is happening as they share the final hours together (Fridh, et al., 2009b:116).

23. *Find out about patient's and families' wishes, culture and traditional practices and respect them when necessary* – **strength of evidence IV**

- Performance of rituals can only be supported if they do not interfere with the care of other patients and their families (Carey & Cosgrove, 2006).

Discussion of evidence

Knowing and following patient's wishes for EOL care has been identified as one of the facilitators to providing a good death (Beckstrand, et al., 2006:41). It has been reported that nurses generally feel emotionally better about a patient's death when they are able to honour the patient's last wishes (Badger, 2005a:520). As reported by nurses at the public tertiary academic hospitals, patients' and families' wishes, cultural practices and traditions should be respected as long as it does not affect the care of other patients and families.

4.4.3 Negative factors impacting on caring recommendations

Recommendations on negative factors impacting on caring at end-of-life are presented as follows:

1. *As much as possible, avoid stressful impulses and sensory disturbances by promoting decreased noise level and a peaceful and quiet ICU environment* – **strength of evidence IV**

- Minimize noise from staff conversation and alarms as they are the most disturbing noises for patients in ICU (Xie, Kang & Mills, 2009).

Discussion of evidence

Noise in the ICU environment has been identified as a constant barrier to providing quality EOL care (Zomorodi & Lynn, 2010a:92). Good nursing care relate to protecting patients against distressing impulses and sensory imbalance (Hov, et al., 2007a:335). In spite of this, nurses including the families at the public sector tertiary academic hospital acknowledged that ICUs are very noisy and there is a need for this to be rectified to enhance patients' comfort.

2. *Clarify with family members their understanding of the patient's illness and treatment options, communicate effectively and if possible, have all family members together in a meeting for explanations and conflict resolutions* – **strength of evidence II**

- Adequate communication is an important determinant of satisfaction with EOL care in the ICU (Cohen, et al., 2005; Downey, Engelberg, Shannon, et al., 2006).

Discussion of evidence

Patients' families' anger, discord concerning the direction of patient's care, and lack of understanding and acceptance of the patient's poor prognosis have been identified as the biggest obstacles to appropriate EOL care in the ICU (Beckstrand & Kirchoff, 2005:397). Furthermore, nurses at the public sector tertiary academic hospitals reported that family discords are a source of stress and this should be solved by having a meeting with all the family members if possible for a so as to come up with a solution to the problems. Effective communication and conflict resolution between the physician and the family members are important (Gries, et al., 2008:710).

3. *Relieve the nurse of all other responsibilities in order for him or her to have time to focus on caring for the dying patient and the family* – **strength of evidence IV**

Discussion of evidence

As expressed by nurses at the public sector tertiary academic hospitals, they would like to support both the dying patient and the family but it may not be easy as they are expected to perform other duties in the unit. This includes having to abandon the grieving families so as to prepare for admission of another patient. Staffing patterns, shortage of nurses and lack of time has been identified as one of the barriers to facilitating a good death because various assignments to the nurse do not allow for needed time in caring for the dying patient and the family (Beckstrand, et al., 2006:40; Zomorodi & Lynn, 2010a:92). For them to offer quality end of life care, nurses have recommended that they would like support staff to assist so that they can focus on meeting the needs of the grieving family (Crump, et al., 2010:303).

4. *Working as a team, discussions should be held among nurses and doctors as a way of preparation towards moving from curative to palliative care. In order to deal with undue distress caused by moral and ethical issues, the rationale for decisions should be clearly understood by all parties and each individual should have a chance to express any concerns they might have regarding EOL care* – **strength of evidence II**

Discussion of evidence

Having consensus about medical treatment among staff, the patient and the family is one of the most important supportive factors in EOL care (Badger, 2005; Beckstrand & Kirchoff, 2005). Nurses at the public sector tertiary academic hospitals expressed the desire to be on the 'same page' with other health care team concerning decisions about EOL. In most cases, physicians decided and after the decision they informed the nurses about the decision they had made. Nurses' opinions were not valued in most cases. In some instances, nurses did not agree with the physicians' decisions; they thought that the decision was prematurely made and because of this, they continued certain interventions that were required to be stopped with the hopes that the patient would recover. It is important that nurses feel adequately supported in these roles and responsibilities so that they can continue to provide the best quality care to patients and their families (McMillen, 2008:258).

4.4 SUMMARY

This chapter presented the tentative best practice guidelines in a form of recommendations. The steps followed in the development of best practice guidelines have been presented. An outline of the conclusions drawn from stage I is provided followed by conclusions integrated and synthesized from step 1-4 including the developed recommendations. Each of the developed recommendation has been supported by a discussion of evidence categorized according to the strength of evidence.

The following chapter deals with verification of the tentative best practice guidelines for EOL care.

CHAPTER 5
VERIFICATION OF THE BEST PRACTICE GUIDELINES ON END-OF-LIFE CARE

5.1 INTRODUCTION

In the previous chapter, methodology and the tentative Best Practice Guidelines (BPG) for intensive care nurses on End-Of-Life (EOL) care were developed and presented. In this chapter, the methodology and results of the verification of the best practice guidelines for intensive care nurses at EOL are presented. Verification process and its results relate to stage III of the study. For clarity, refer to **figure 5.1** for the summary of the process of presenting this chapter.

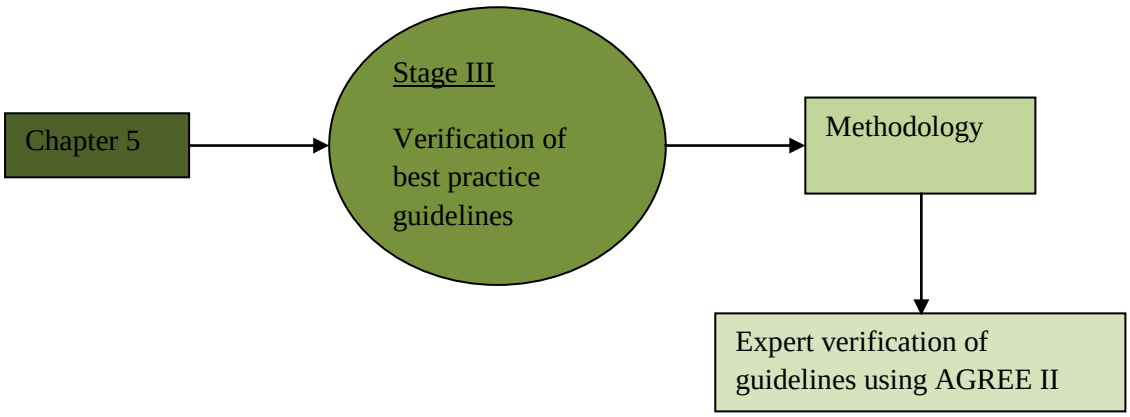


Figure 5.1 A summary of the presentation of chapter 5

5.2 METHODOLOGY OF VERIFICATION OF THE BEST PRACTICE GUIDELINES

5.2.1 Target population

The target population for expert participants to verify the best practice guidelines included all personnel from different disciplines that have had an experience in the nursing care of a patient at EOL and his or her family in the ICU.

5.2.2 Sampling and sample

A non probability purposive sampling method was used to select the personnel in the different disciplines to verify best practice guidelines. Although not all of them were working in the ICU at the time of guideline verification, all of them had previously had an experience of caring for the patients at EOL including their families in the ICU. AGREE II instrument (refer to **appendix AA**) was used in this process of best practice guidelines verification. AGREE research trust (2009) recommend that each guideline is assessed by at least two appraisers and preferably four as this will increase the reliability of the assessment. Four (n=4) verifiers were used in this stage. These included:

- A professor of intensive care nursing at a University
- A trauma and critical care nurse with a doctorate degree at a University
- A nursing service manager with a critical care specialty from an academic hospital
- A critical care lecturer at a University who is also a member of the Critical Care Society of Southern Africa, and a representative of the Society on the council of the World Federation of Critical Care Nursing

5.2.3 Verification procedure

The verification process was intended to assess the quality of the best practice guidelines, refine and further develop the guidelines and ensure its content validity. This process was undertaken using the AGREE II instrument (AGREE research trust, 2009). The purposively selected verifiers were approached by the researcher and informed of their selection as expert reviewers for verification of the best practice guidelines. Following a verbal consent, the researcher forwarded a parcel containing an information letter, consent form (refer to **appendices AB** and **AC** respectively), the tentative best practice guidelines for critical care nurses (refer to **table 4.2)** and an AGREE II instrument users guide (AGREE research trust, 2009) attached to the AGREE II instrument (refer to **appendix AA**) to all verifiers.

The best practice guidelines were rated on a 7-point scale with 7 for ‘strongly agree’, 1 for ‘strongly disagree’ and a score between 2 and 6 was assigned when the AGREE II item did not meet the full criteria or considerations. Scores increase as more criteria are met and

considerations addressed. A space for comments and two for overall assessment of best practice guidelines is provided at the end of the AGREE II instrument. The expert reviewers were requested to comment as to whether they would recommend the guidelines for use, recommend with modifications or would not recommend. They were asked to rate the overall quality of the guideline with 1 being the 'lowest possible quality' and 7 being the 'highest possible quality'. This overall assessment was used to make a judgement of quality of the best practice guidelines.

5.2.4 The AGREE II Instrument

AGREE II instrument developed by the AGREE research trust (2009) provides a framework for assessing the quality of clinical practice guidelines, refine and further develop best practice guidelines and ensure content validity of best practice guidelines. Quality best practice guidelines means the confidence that potential biases of guideline development have been addressed and that the best practice guidelines are both internally and externally valid, and are feasible for practice. In addition, the AGREE II instrument assesses the benefits, harms and costs of the recommendations and the practical issues related to the implementation of the best practice guidelines. The AGREE II instrument is used to assess new best practice guidelines, existing best practice guidelines and BPG that have been updated. For the purpose of this study, the AGREE II instrument was used to verify new best practice guidelines.

AGREE II instrument consists of 23 key items organised in six domains. Each domain is intended to capture a separate dimension of guideline quality as described below.

Domain 1: Scope and Purpose- Is concerned with the overall aim of the guideline, the specific health questions and the target population **(Items 1-3)**.

Domain 2: Stakeholder Involvement- Focuses on the extent to which the guideline was developed by the appropriate stakeholders and represents the views of its intended users **(Items 4-7)**.

Domain 3: Rigour of Development- Relates to the process used to gather and synthesise the evidence, the methods to formulate recommendations and to update them **(Items 8-14)**.

Domain 4: Clarity of Presentation- Deals with the language, structure and format of the guideline **(Items 15-17)**.

Domain 5: Applicability- Pertains to the likely barriers and facilitators to implementation, strategies to improve uptake and resource implication of applying the guideline **(Items 18-21)**.

Domain 6: Editorial Independence- Is concerned with the formulation of recommendations not being unduly biased with competing interests **(Items 22-23)**.

A quality score was calculated for each of the six AGREE II domains. Domain scores were calculated by summing up all the scores of the individual items in a domain and by scaling the total as percentage of the maximum possible score for that domain. Although the domain scores are useful for comparing guidelines and informs whether a guideline should be recommended for use, the consortium has not set minimum domain scores or patterns of scores across domains to differentiate between 'high quality' and 'poor quality' guidelines (AGREE research trust, 2009). Since no universal agreement exists about specific cut off scores to identify high quality guidelines, a slightly higher score of 70% was considered by the researcher as an acceptable quality score so as to ensure adequate reliability. Based on this, the decisions on whether a guideline should be recommended for use was made by the verifiers guided by the set scores. Feedback, recommendations, criticisms and suggestions were analysed and incorporated into the guidelines by the researcher

5.2.5 Validity and reliability of the AGREE II instrument

The AGREE II instrument which was used to verify best practice guidelines is a valid and tested tool by the AGREE research trust (2009) hence its validity and reliability is assured.

5.3 RESULTS OF VERIFICATION OF THE BEST PRACTICE GUIDELINES

In this section, the feedback, recommendations, criticisms and suggestions from the verifiers are discussed for each of the six domains. The six domains assessed by the AGREE II

instrument include: scope and purpose, stakeholder involvement, rigour of development, clarity of presentation, applicability and editorial independence.

5.3.1 Scope and purpose

Scope and purpose was the first domain of the best practice guidelines. This concerned the overall aim of the guidelines, the specific health questions, and the target population (items 1-3). Refer to **table 5.1** for the verifiers' assessment of the scope and purpose of the best practice guidelines.

Table 5.1 Verifiers' assessment of the scope and purpose

Appraiser	**Item 1**	**Item 2**	**Item 3**	**Total**
1	6	6	6	18
2	5	5	6	16
3	5	5	6	16
4	6	7	7	20
Total	**22**	**23**	**25**	**70**

For clarity, an example on how to calculate each of the six domain scores is provided using domain one. AGREE II instrument consists of 23 key items organised in six domains. The verifiers rated the best practice guidelines on a 7-point scale from 7 for 'strongly agree' to 1 for 'strongly disagree'. Domain scores were calculated by summing up all the scores of the individual items in a domain and by scaling the total as percentage of the maximum possible score for that domain (AGREE research trust, 2009:9). An illustration using the first domain is as follows:

- Maximum possible score = 7(strongly agree) x 3(items) x 4(appraisers) = 84
- Minimum possible score = 1(strongly disagree) x 3(items) x 4(appraisers) = 12

The scaled domain score = $\frac{\text{Obtained score – Minimum possible score}}{\text{Maximum possible score – Minimum possible score}}$

$$= \frac{70 - 12}{84 - 12} = \frac{58}{72} = 0.8055 \times 100 = 81\%$$

A score of 81% was obtained for the scope and purpose domain of the best practice guideline.

Verifiers made the following comments:

- Under item 1, there was a need to include reference to the South African Nursing Scope of Practice (The South African Nursing Council, 2008) bearing in mind the scope of guidelines is intended for South African intensive care nurses. To deal with this comment, reference to the South African Nursing Scope of Practice was included during guideline development stage.
- For item 2, there was a need to ensure the concept of intensive care nurse and families is well defined as this may mean different things to different people. Due to this, these two concepts have been clarified within the best practice as well as under the definition of terms section in chapter one.

5.3.2 Stakeholder involvement

The second domain was stakeholder involvement and this focused on the extent to which the guideline was developed by the appropriate stakeholders and represented the views of its intended users (items 4-6).**Table 5.2** presents the results of the verifiers' assessment of the stakeholder involvement.

Table 5.2 Verifiers' assessment of the stakeholder involvement

Appraiser	**Item 4**	**Item 5**	**Item 6**	**Total**
1	5	6	6	17
2	6	6	6	18
3	6	6	6	18
4	7	7	4	18
Total	**24**	**25**	**22**	**71**

The scaled domain score = $\frac{\text{Obtained score – Minimum possible score}}{\text{Maximum possible score – Minimum possible score}}$

$$= \frac{71 - 12}{84 - 12} \quad = \frac{59}{72} \quad = 0.8194 \times 100 = 82\%$$

A score of 82% was obtained for the stakeholder involvement domain of the best practice guideline.

Verifiers made the following comments:

- For item 5, it was not clear to the verifiers whether doctors' views and preferences were sought during the study. To answer this, it is acknowledged as a limitation of the study that doctors were not included in the study and their views did not form part of the guidelines. The inclusion of doctors is provided for as a recommendation for further research.
- For item 6, the need to incorporate the doctors when implementing guidelines so as to ensure ownership and collaboration was stressed by the verifiers. Recommendations have been made for clinical practice and further research concerning this issue.

5.3.3 Rigour of development

The third domain was **rigour of development** of the best practice guideline. This related to the process used to gather and synthesize the evidence, the methods to formulate the recommendations, and to update them (items 7-14).**Table 5.3** presents the results of the verifiers' assessment of rigour of development.

Table 5.3 Verifiers' assessment of rigour of development

Appraiser	**Item 7**	**Item 8**	**Item 9**	**Item 10**	**Item 11**	**Item 12**	**Item 13**	**Item 14**	**Total**
1	5	6	6	6	6	6	6	6	47
2	5	6	6	7	5	6	6	5	46
3	6	6	7	6	6	7	6	6	50
4	7	7	7	7	7	6	7	7	55
Total	**23**	**25**	**26**	**26**	**24**	**25**	**25**	**24**	**198**

The scaled domain score = $\frac{\text{Obtained score – Minimum possible score}}{\text{Maximum possible score – Minimum possible score}}$

$= \frac{198 - 32}{224 - 32} = \frac{166}{192} = 0.8645 \times 100 = 86\%$

A score of 86% was obtained for rigour of development domain of the best practice guideline.

Verifiers made the following comments:

- Under item 7, justification for search period during systematic review as well as clarity of the search terms used was required. Justification and clarity of search terms have been provided in chapter 4A. Other search terms mentioned were not used and have been recommended for use during further research.
- Under item 8, there was a need to clarify the percentage of evidence used in the development of guidelines and whether all levels of evidence were used. For clarity, all (100%) evidences were used in the guideline development. Evidences used ranged from level II-V. Level I evidence was not used as this was not available.
- Item 9 needed clarity whether a third reviewer was used in instances where the first and second reviewer disagreed. For this case, there was no disagreement between the two reviewers hence there was no need for a third reviewer.
- For item 11, there was a need to clarify whether the health side effects and risks the intensive care nurses face during end-of-life care were considered during guideline development. It is acknowledged that the nurses may face psychological and emotional difficulties while they provide support to other team members, patients and families at end-of-life. For this reason, recommendations have been made to the management to provide support to the nurses in different forms such as through workshops/continuous education/training and debriefing sessions among others.
- To demonstrate an explicit link between the recommendations and the supporting activities under item 12, some of the recommendations made by the verifiers were incorporated in the guidelines.
- For item 14, it was not clear where the time frame for updating guidelines came from. The sources have been clearly provided under guideline development in chapter 5.

5.3.4 Clarity of presentation

The fourth domain was **clarity of presentation** of the best practice guideline. This dealt with the language, structure, and format of the guideline (items 15-17).**Table 5.4** presents the results of the verifiers' assessment of the clarity of presentation.

Table 5.4 Verifiers' assessment of the clarity of presentation

Appraiser	Item 15	Item 16	Item 17	Total
1	6	6	6	18
2	6	6	6	18
3	6	6	6	18
4	6	7	7	20
Total	**24**	**25**	**25**	**74**

The scaled domain score = $\frac{\text{Obtained score – Minimum possible score}}{\text{Maximum possible score – Minimum possible score}}$

$$= \frac{74 - 12}{84 - 12} = \frac{62}{72} = 0.8611 \times 100 = 86\%$$

A score of 86% was obtained for clarity of presentation domain of the best practice guideline. No changes were made to the guidelines as the verifiers were satisfied with the domain.

5.3.5 Applicability

Applicability was the fifth domain of the best practice guideline. This pertained to the likely barriers and facilitators to implementation, strategies to improve uptake, and resource implications of applying the guideline (items 18-21). Refer to **Table 5.5** for the verifiers' assessment of the applicability.

Table 5.5 Verifiers' assessment of applicability

Appraiser	Item 18	Item 19	Item 20	Item 21	Total
1	6	7	6	6	25
2	6	6	6	7	25
3	5	6	6	6	23
4	7	7	7	5	26
Total	**24**	**26**	**25**	**24**	**99**

The scaled domain score = $\frac{\text{Obtained score – Minimum possible score}}{\text{Maximum possible score – Minimum possible score}}$

$$= \frac{99 - 16}{112 - 16} = \frac{83}{96} = 0.8645 \times 100 = 86\%$$

A score of 86% was obtained for applicability domain of the best practice guideline.

Verifiers made the following comments:

- For item 20, one of the potential resource implications of applying the guidelines noted by the verifiers was a need to promote the interaction or communication between the nurses and doctors in ICU regarding end-of-life care through workshops and involvement of other team members to promote support for use of guidelines. This has been recommended under clinical practice section and management.
- For item 21, there was a need to clarify whether the guidelines present monitoring and/or auditing criteria. In order to ensure adherence to the clinical guidelines, recommendations have been made for clinical practice.

5.3.6 Editorial independence

Editorial independence was the sixth domain of the best practice guideline. This was concerned with the formulation of recommendations not being unduly biased with competing interests (items 22-23). Refer to **Table 5.6** for the verifiers' assessment of the editorial independence.

Table 5.6 Verifiers' assessment of the editorial independence

Appraiser	**Item 22**	**Item 23**	**Total**
1	7	7	14
2	7	7	14
3	7	5	12
4	7	7	14
Total	**28**	**26**	**54**

The scaled domain score = $\frac{\text{Obtained score – Minimum possible score}}{\text{Maximum possible score – Minimum possible score}}$

$= \frac{54 - 8}{56 - 8} = \frac{46}{48} = 0.9583 \times 100 = 96\%$

A score of 96% was obtained for the editorial independence domain of the best practice guideline. No changes were made on the guideline as the verifiers were satisfied with this domain.

5.4 OVERALL GUIDELINE ASSESSMENT

In order to make a judgement of the quality of the best practice guidelines, the verifiers were asked to rate the overall quality of the guideline on a 7-point likert scale with 7 being the highest possible quality and 1 being the lowest possible quality. The quality of the guidelines was highly rated by all the verifiers with the highest possible score being 6 from all four verifiers.

In addition to rating the overall quality of the guidelines, the verifiers were asked to recommend the guidelines for use. Two of the verifiers recommended the guidelines for use without modifications whereas two of them recommended the guidelines for use with modifications. Recommendations from the verifiers were incorporated into the tentative guidelines. These guidelines are presented in **table 5.7**.

Table 5.7 Verified best practice guidelines for intensive care nurses on end-of-life care

	Communication recommendations
1	While managing medical and technological challenges, a nurse should offer explanations, interact and practice verbal/nonverbal communication even to the unconscious and/or critically ill dying patient to uphold humanity
2	Since South Africa is a culturally diverse nation, a nurse should find out about a patient's and families' preferred language of communication and ensure that there is no language barrier during nursing care delivery which may lead to miscommunication and compromise patient/family-nurse relationships
3	In order to reduce misunderstandings about the goal(s) of care, obtain a living will from the patient early in the care or inquire about existence of a living will and respect the patient's wishes for EOL care
4	If a patient has a decision making capacity, he or she should be involved in every decision concerning his/her treatment. If the patient has no decision making capacity, discussions about EOL care should be held with the family as a way of communicating the patient's wishes and honouring the patient's choices
5	Prepare the families for what to expect. The doctor or a nurse should always be available to clearly communicate and offer a daily patient progress report from the first day of admission despite the prognosis
6	Have either one nurse or doctor to act as the family contact person. If not possible, there should be continuity of patient care and nurses and doctors should be as consistent as possible so as to avoid conflicting information and confusion
7	Although it may not be easy to predict what will happen, the doctor should inform the family of "what to expect" once a not for resuscitation order has been given. Continue answering questions, offering information of what to expect regarding changes in the patient's status and support family members even after the patient's death
8	Encourage collegiality. Carry out effective communication with mutual respect between nurses, patient, families and the treating doctor for quality EOL care
9	Have one family member as a designated contact person and provide information about the patient to the family on a regular basis to reduce the number of incoming calls handled by nurses

10	Involve nurses in the doctor-family meetings including EOL discussion and decision making processes
11	When the primary goal of care has shifted from cure to comfort care, it should be made known by the treating doctor to the nurses verbally and through clear written documentation on the patient's chart. Futile care should be avoided by an open discussion and agreement on what "no escalation of care" means between the treating doctors and nurses – to reduce frustration for nurses which may affect patient/family care during EOL
Caring recommendations	
1	Assess for pain and discomfort and manage as necessary. Where orders are not in place, advocate for the patient to receive drugs for symptom relief. Continue interventions to ensure comfort throughout EOL care
2	Reassure families and emphasise the fact that the patient will be kept as comfortable as possible
3	Despite the poor prognosis, a nurse should not withhold basic nursing care during EOL care
4	Encourage and allow families if they are comfortable to take part in direct care of the patient; which can be done under supervision
5	The nurse/doctor should show empathy to both the family and the patient, listen to the family attentively, address concerns and provide frequent contact and presence
6	As per the patient's/family's requests or wishes, (if relevant), allow their own religious leaders access to the unit to provide spiritual support
7	The nurse should assess the need for spiritual support and discuss with the patient/family the possibility of offering such support if comfortable. If not, liaise with the family and organize for a religious leader to come and provide support
8	The hospital should make a list of available religious leaders/appoint a religious leader(s) on standby to offer spiritual support when needed, especially for those patients/families that need the support but do not have any religious leader
9	Encourage families to stay with the patient whilst dying. Where families are (not) around, nurses should be present by the dying patient's bedside so that the patient does not die alone.
10	Provide, and discuss with the families flexible visitation policies

11	Explain to the family why the nurse is leaving the room. In spite of various activities that need to be done outside the patient's room, nurses should create time to be with the family at the bedside as a form of support. The nurse should inform the family why he/she is leaving the room, which could decrease stress
12	Teach the patient's family members how to act around a dying patient, encourage them to touch and speak to the patient
13	Offer continuous education on skills, knowledge and attitude on how to support patients and families at EOL especially to the newly qualified, inexperienced and junior nurses
14	Encourage collegiality and collaboration so as to work towards the same goal for the best EOL care
15	Discuss the availability of expert additional support services for a dying patient and grieving families. If required, organize for support from either a social worker, psychologist, or a religious leader
16	Assess emotional reactions of the staff while caring for the a dying patient and institute support mechanisms such as debriefing sessions by a counsellor
17	Allow nurses a few hours to grieve, recover and be able to move on after a patient's death and before a new admission since EOL care could be exhausting and draining
18	As a nurse's coping strategy, let a group of nurses take turns caring for a dying patient by means of change of shifts on a daily basis
19	Assess the ability of a nurse who has recently been bereaved in engaging in EOL care. Support those nurses who may not wish to engage in EOL care until they have coped with their own lose and have indicated their readiness
20	To maintain patient's privacy, always keep the patient's body covered or screen the patient when conducting procedures that need bodily exposure
21	As per their wish, allow the family time with the patient in private in preparation for death
22	If possible, move or nurse the patient in a single room to promote confidentiality and privacy for the dying patient/family and to protect other patients in the unit from disturbing scenes
23	Find out about patient's and families' wishes, culture and traditional practices and respect them when necessary

Negative factors impacting on caring recommendations	
1	As much as possible, avoid stressful impulses and sensory disturbances by promoting decreased noise level and a peaceful and quiet ICU environment
2	Clarify with family members their understanding of the patient's illness and treatment options, communicate effectively and if possible, have all family members together in a meeting for explanations and conflict resolutions
3	Relieve the nurse of all other responsibilities in order for him or her to have time to focus on caring for the dying patient and the family
4	Working as a team, discussions should be held among nurses and doctors as a way of preparation towards moving from curative to palliative care. In order to deal with undue distress caused by moral and ethical issues, the rationale for decisions should be clearly understood by all parties and each individual should have a chance to express any concerns they might have regarding EOL care

5.5 SUMMARY

This chapter presented the methodology and results of the verification of best practice guidelines. In general, the guidelines were rated as of high quality and with modifications, they were recommended for use by the verifiers.

The following chapter presents an evaluation, recommendations, limitations and a conclusion of the study.

CHAPTER 6

EVALUATION OF THE STUDY, LIMITATIONS, RECOMMENDATIONS AND CONCLUSION

6.1 INTRODUCTION

In the previous chapter, the results of the Best Practice Guideline (BPG) verification process were presented. This final chapter presents an evaluation of the study, outlines the limitations of the study and offers recommendations for management, nursing education, clinical practice and further research. Conclusion of the study follows at the end of it.

6.2 EVALUATION OF THE STUDY

This section presents an evaluation of the study which is presented in the form of a review of the five chapters in the study.

In **chapter one**, an overview of the study was provided. This entailed an introduction to the study, the background of the study and the problem statement that prompted the need to conduct the study. In it also was the purpose of the study which was to develop best practice guidelines for End-Of-Life (EOL) care for intensive care nurses in adult Intensive Care Units (ICUs) at tertiary level III hospitals in Gauteng province. To achieve this purpose, the following objectives were set: 1) To search and analyze for quality research discourse on end-of-life care by means of a systematic review, 2) To search for evidence on end-of-life care through interviews with family members, interviews with critically ill patients and focus group discussions with intensive care nurses, 3) To develop best practice guidelines for intensive care nurses on end-of-life care and 4) To verify the tentative best practice guidelines for intensive care nurses using an Appraisal of Guidelines Research and Evaluation (AGREE) II instrument.

Furthermore, the significance of the study including the researcher's paradigmatic perspectives and relevant definitions to the study were described. An overview of the

research design and methodology used followed including measures to ensure validity and reliability as well as ethical considerations.

An overall research design and method was provided in **chapter two**. This included discussion related to the research setting, researcher's worldview in qualitative studies, methods of data analysis, ethical considerations and how to ensure trustworthiness of the study. Both quantitative and qualitative designs were used in the process of developing best practice guidelines on EOL care for intensive nurses. The process of best practice guideline development was divided into three stages.

Stage I refers to the first and second objectives of this study. This involved the search for quality research evidence which was conducted in four steps. Step 1 involved collecting evidence by means of a systematic review. Step 2 involved collecting evidence on the family members' experiences of EOL care by means of semi structured interviews. Step 3 involved collecting evidence from the critically ill patients' experiences of comfort care by means of semi structured interviews. Step 4 involved collecting evidence on intensive care nurses' experiences of EOL care by means of focus group discussions.

Stage II refers to the third objective of this study. This dealt with the development of the tentative best practice guidelines. This involved integrating and synthesising quality research evidence, development of best practice guidelines and categorising the strength of the evidence. Stage III refers to the fourth objective of this study which involved the verification of the tentative best practice guidelines.

Chapter 3A refers to step 1 of stage I. In this chapter, the process of conducting a systematic review including its results was reported. A systematic review was conducted in order to provide a rigorous review of quality research evidence, expert practitioners' opinions, patients' preferences and available resources to deliver recommended comfort care necessary at EOL. The review was based on a systematic search on six databases including: SCOPUS, Science Direct, Pub med, Cochrane, Medline and CINHAL. In addition to electronic

searches, journal hand search, reference lists of articles, books, theses and Government documents was also conducted.

The search pathway was carried out using the search words comfort care, end-of-life care, palliative care, intensive/critical care and futile care in the ICU. The inclusion criteria included articles with full text in English language, a focus on adult EOL care (19 years and older) ICU population, studies undertaken between the year 2003 and 2011 and published abstracts only. Both peer reviewed qualitative and quantitative studies were included in the search.

The process of conducting a systematic review included question formulation, conducting the literature search, appraisal of retrieved literature and data synthesis. In order to ensure validity of the systematic review, all literature were appraised prior to inclusion in the systematic review, bias was reduced by use of multiple electronic databases as well as journal hand searches and reference lists of relevant articles. Reliability was maintained by ensuring consistency in the selection of literature by adherence to predetermined inclusion criteria and by involving a co-reviewer during the systematic review so as to ensure accuracy and reliability of selected information.

In total, the search yielded 23 articles of which, its quality assessment revealed that they all had scores above 70% which was a cut off point agreed between the two reviewers in this study. During data synthesis, heterogeneity of the design, population, setting, presence of an intervention and perspectives precluded meta-analytic techniques to statistically combine data hence the findings were summarized and then a detailed qualitative description was done. The review revealed several results from various authors as summarized in **table 3A.4**. Following the process of coding, co-coding and thematic analysis, related results were further grouped together by the researcher into three main themes/categories including: factors that enable or complicate EOL care, patients'/family members'/nurses' experiences of EOL care and decision making processes. These main areas are discussed briefly in the section below.

To begin with, factors that enable EOL care and supportive behaviours towards quality EOL care that helped nurses to move toward comfort care included consensus among patients, patients' families and staff about the direction of medical therapy, exhausting treatment options and patients' lack of responses to aggressive medical interventions. In addition, providing a dignified death, not allowing the patient to be alone while dying, managing patient's pain and discomfort, knowing and then following through patient's wishes for EOL care, promoting earlier cessation of treatment and not initiating aggressive treatment at all, communicating effectively as a health care team, providing clear, direct and consistent information, continuity in nursing care, nurses' knowledge, nurses' competence, cooperation and educational initiatives for professionals and public were also suggested as some of the factors that improve quality of EOL care and promote a good death in the ICU.

On the other hand, the barriers towards quality EOL care identified in this review included: misunderstanding of the illness by patient's family, family discord and shifting medical care decisions, providing futile care, limited nursing time, constraints, rigid staffing patterns, communication challenges, treatment decisions that were based on physician rather than patient needs, behaviours of families that remove nurses from caring for patients such as frequent phone calls, behaviours that prolong patient's suffering or pain, physician's disagreement about the plan of care and lack of nurses' knowledge, skills and sense of cultural competency to provide quality EOL care.

In terms of experiences of EOL care, the review revealed that doing one's utmost was dominated by the nurses' endeavour to provide dignified EOL care and, when relatives were present, to offer them support during their time of grieve. It was considered tragic when a patient died without the presence of a family member and in such cases, nurses provided warm and compassionate care to the unaccompanied patients by never leaving them alone during the dying process.

Frustration with physicians and communication problems between physicians, nurses, patients and families was also expressed by nurses in these reviews as contributors to their

dissatisfaction. Nurses reported that physician authority in discussion and decision making was acknowledged and that even though providing information to the patients is something that nurses know they should do, they expressed reluctance to do so fearing reprimand by the physician. Nurses expressed the need for physicians to speak frankly with family members so as to promote family satisfaction and avoid family distress during EOL care.

During their caring process, nurses also stated that they may lack knowledge and skills in EOL care, find caring for dying patients and their families stressful and lack support to provide this care. Apart from this, participants reported the importance of care of relatives, religious support, ensuring patient's symptom control and comfort measures (such as pain control, hygiene, positioning and suctioning) family being more often involved in decision making and encouraged to be involved in the care of their loved one as these contributed partly to their satisfaction of care rendered to their loved one.

Family members in the review also described their experiences and feelings when a loved one was receiving EOL care in the ICU. They reported that their dying loved one's serious condition and his or her dependence on the medical-technical equipment were experienced as more frightening than the equipment as such. Being confronted with the threat of loss, they maintained a vigil while at the same time trusting the care provided to their loved one and trying to adapt/understand the whole situation. The family reported the need for privacy and togetherness so as to experience reconciliation. It was also reported that adequate communication, good decision making, and respect and compassion shown to both the dying patient and their family were key determinants to family satisfaction.

In addition, they (family) wanted to be informed of any changes, have an opportunity to discuss treatment and have questions answered by nurses and doctors, have the same group of nurses provide care for consistency, have one hospital staff member act as the family contact so as to avoid confusion, have time with the patient in preparation for death and eventually have flexible visitation policies which maximize access between family members, their dying loved one and health care professionals.

Finally, the findings on discussion and decision making during EOL care in this review revealed that nurses perceived physician as the rightful initiator of discussion as well as the final decision maker. Nevertheless, a European study showed that most nurses were involved to a large extent in EOL decisions, but not as initiating the discussion and once a decision was made there was a sense of agreement between the health care team. It was also reported that senior nurses are often actively involved in EOL decisions than junior nurses because senior nurses have more experience and are naturally likely to be involved. Less involvement was associated with cultural differences in different countries. Of most importance, nurses reported their role in supporting the family and being a patient advocate during this tough moment. Above all, the results indicated that nurses should be more involved in family-physician communication/decisions and contribute to building a team for family support.

In most cases, it was shown that relatives want a more active role in EOL discussion and decision making in order to communicate the patient's wishes. However, many considered their role to be unclear, and few of them experienced shared decision making. In addition, EOL decisions were discussed with the family in some of the cases and in some, the families were more often told than asked about EOL decisions. Discussions did not occur with families in many cases because the patient was unresponsive to maximal therapy or because the physician believed that the family would not understand. Family-physician disagreements that arose were significantly associated with less family satisfaction with decision making and decreased feelings of support during the process. This review also reported that family members felt more support and were more satisfied with the decision making process when spirituality was addressed during family meetings.

In chapter 3B, which refers to step 2 of stage I, the experiences of family members on EOL care were elicited and provided. Five themes were identified and they included: "most of the time we are in darkness", "emotional support", "involvement", "you feel you should see her face more often" and "spiritual support". In brief, the findings from the families were as follows:

One of the important needs raised by all family participants was communication and receiving information. Even though they all needed to be given information regarding their critically ill family members, they were not satisfied about how this was done, as they felt they were not given all the necessary information they needed. Due to inadequate information, the families felt like they were left in darkness most of the time. In order to obtain answers to their questions, they had to ask. Similarly, they needed a daily report about the patient's status but this was not available. It was frustrating when they wanted to ask, the doctors were busy and the nurses would not or did not want to divulge the information. The families had to wait for the doctor and sometimes they had to go home without getting the information they needed to know.

Moreover, it was confusing when the families found different staff members caring for the patient giving contradicting information. This not only raised some mistrust but also portrayed a lack of unity and communication among the staff. Information as to what to expect and what to do from the time when a decision of "not for resuscitation" was made till death was not available for the families. In such instances, families were left to wonder what to do and how to do things while they waited for the death to occur.

Of significance, all families expressed emotional disturbances and the need for support at such a difficult time in their lives. Hope was common in all families and, despite being told about their relative's poor prognosis; they still hoped that a miracle would happen and that the patient would get well. In spite of the outcome, the families wanted to be reassured that their loved ones would be kept as comfortable as possible in terms of pain management and hygiene. They all acknowledged that their family members appeared clean and comfortable. One concern raised was noise from the staff as families thought this could have caused discomfort to ICU patients as much as it was to them.

The reception to ICU was considered by the majority as inadequate. Patients' families expected hospitality and empathy but this was not provided by all the nurses. In order to decrease their stress level, families mentioned that they needed someone to talk to as well as

to encourage them. Ideally, nurses should have been available for these families to provide emotional support and information till the end. However, it was reported that the nurses were not always in the patients' rooms. Frequently, when the nurse came to the room, she took a few minutes to attend to the patient and left again and (when she could talk to the family) this would be done hastily. This behaviour from the nurses made families feel unwanted.

The other major finding from the interviews was the lack of family involvement in decision making and direct patient care. All families wanted to be involved in the decision making process regarding the care of their loved. Unfortunately, this was not done as they were often told about the decisions that had already been made rather than being involved in the decision making process. The families felt they should be included in the whole process as they are in a better position to know the patient's preferences than the ICU team. They also felt that they were in a position to advocate for the patient. Mostly, they felt as if the decisions came from the physician and neither the nurse nor the family could object since, once the decision was made, the care was steered in that direction. Moreover, participants wished to be involved in the direct care of their loved one. Although this was their wish, the settings where the research was done do not allow families to participate in patient care in the ICU. Nevertheless, families expressed the need for supervision and nurses' presence if they were able to assist with caring for the patient so that they can know what to do and what not to do.

A further issue that emerged from the interviews is the need to access the patient at any time. All families except two expressed the need to be with their ill family member whenever they wished. Visiting time for families of patients at end of life is always open in these settings. It appeared that some families were not informed about this benefit. To them waiting from one visiting time to the next one was too much as they kept thinking about what could be happening when they were away from the patient's bedside. Being at the hospital reassured them as they were able to see the patient still alive.

Finally, spirituality was another aspect that emerged from the interviews with the families. All families valued religion and the support from their religious leader as a form of support

during this difficult time. Even though they did not receive such a support from the ICU team, they all prayed for the patient and, at the same time they approached their religious leader to encourage them and to pray for the patient. Spirituality was viewed as a source of hope to recovery, and when recovery was not possible, a way of making peace and allowing the patient to die peacefully in a dignified manner.

In **chapter 3C** which refers to step 3 of stage I, the experiences of critically ill patients on comfort care were elicited. In this chapter, five major themes emerged. They included: "Being in someone's shoes", "communication", "trust", "presence" and "religion and spirituality". The findings from this chapter are briefly discussed as follows:

The patients' desire to be cared for by someone who would feel and understand what they are going through while admitted in the ICU appeared as one of the major findings from the interviews. Although compassion including psychological care or reassurance was not valued all the time by the nurses, it meant a lot to the patients. Nurses' compassion and reassurance meant that the nurses cared and contributed to their psychological satisfaction and decreased anxiety.

Apart from being satisfied with maintenance of their personal hygiene, patients also wanted their dignity to be upheld by the nurses. In addition, inadequate pain management appeared to be the most common problem for the patients interviewed in this study and this reflects how uncomfortable the majority of the patients were. To add to their discomfort, it was reported that the ICU was too noisy and this contributed to disturbances in sleep and relaxation.

Of significant from the patient participants' interviews also was communication. The majority of the patient participants were not happy with communication between them and the nurses. Even though they were not able to respond or talk, most of them could hear but seemingly their non-responsiveness might have let to decreased amount of communication from the nurses. It felt like intrusion of privacy when the nurses went ahead with the interventions (as it happened to some patients) without explaining the procedure or informing

the patient about what was about to be done beforehand. It was also evident that patients desired to receive information in a language they could understand and to be oriented not only about interventions but also about what was happening in their surroundings.

Although technology contributes to caring, it was found that some nurses concentrated much on the machines and equipment with less attention directed to the patient. When lack of attention and communication occurred, patients felt neglected and they appeared just like an object of care and not human beings. It is thus thought that communication with sedated or unconscious patients in ICUs should not be viewed as only an interactive process. Rather, it should be perceived as a means of providing the information and support that such patients need hence reduced amount of stress.

While some patients trusted the nurses with their personal information and their care, others had lost faith in them. The loss of trust in the nurses was mainly due to the way nurses treated the patients. Lack of respect and unprofessional behaviour towards the patient contributed to a loss of trust in the caring nurse. In addition, as mentioned by some of the participants, the nurses' lack of knowledge and inability to communicate and share information to the patient were also regarded as sources of mistrust between the nurse and the patient.

Of importance to the patient participants also was presence. The presence of a nurse at the patient's bedside was valued by all the study participants as a source of relief, safety and security. Even though it may not be practical for the nurse to be at the patient's bedside throughout, the nurse should make an effort to attend and respond to the patient's needs on a regular basis. This will serve to alleviate worries and anxieties that were found to be common in study participants in this study.

The presence of family though not valued by two of the patients was considered to be of importance by most of the participants. Those who did not want family to be around believed they were comfortable in the hands of the healthcare providers. They perceived the presence

of family and friends as a threat to their lives because they did not want families to know about some things going on in their lives.

Those who mentioned that the presence of the family is important wanted more time with them outside visiting hours as they did not only get encouragement from them but it also made them feel safe. While some wished the family could participate in their care, some wanted the family to be involved in the decision making process as this was the only way their preferences could be known to the health care personnel especially during the time they were critically ill and not able to communicate.

Finally, religion and spirituality which arose as one of the major findings in this study was valued by all the patients. In most cases, patients prayed for themselves in their beds. Prayers gave them solace, hope for recovery and drew them closer to God. While most of them received spiritual support from the family and friends, this was seldom offered by the nurses or ICU team except in one occasion where a nurse prayed with one of the patients.

On the other hand, patients also valued spiritual support from religious leaders. Whereas some of them wanted such a support only from the religious leaders known to them, others did not mind having any religious leader coming to pray for them. Bearing in mind that patients came from culturally diverse population with different religious backgrounds, those who did not want prayers from unknown people believed that prayer is about believing what the bishop/father/priest/pastor says and where he comes from. This division about who should offer the spiritual care showed that ICU team should bear in mind about the patients' religious backgrounds and respect their preferences if they have to organize or allow religious leaders to offer such a care in the ICU.

In **chapter 3D** which refers to step 4 of stage I, intensive care nurses' experiences of EOL care were elicited through three focus group discussions. From these discussions, five major themes were identified including: "difficulties we get", "discussion and decision making",

“support for patients”, “support for families” and “support for nurses". The following section summarises these findings.

First of all, nurses reported that it is challenging to care for the patients at EOL including their families and this was expressed in various ways. Among them, nurses found it challenging psychologically and emotionally especially when they had to care for younger patients or patients that had been in the unit for a longer period. The difficulty of letting go was associated with the bond that had developed between the patient and the family. As humans, nurses also felt emotionally disturbed expressed as painful, heartbreaking and draining among others when they saw such patients suffering and slowly dying.

In terms of communication with families, the nurses had difficulties concerning whether to talk to them or not about the patient’s prognosis and progress. While nurses thought that talking could lead to confusion and misinformation, they also thought that it was tricky because the family could use their words to put them in trouble. In most cases, they would refer the family to the doctor for any explanations needed. The other reason given as to why nurses were reluctant to talk is because it was not in their scope of practice to do so.

Moreover, dealing with families in denial was also reported to be a challenge. Whereas a few regarded such families as troublesome, the majority tried to accommodate them as they understood that it was part of the stages of grieving and that families needed time to come to terms with the news. Despite the need to end patient’s suffering, it was not easy to initiate limitation of treatment especially in patients who had been in the unit longer and had developed relationships with the nurses. A few nurses generally found it totally difficult to start limiting life sustaining therapies such as inotropes. The reason behind this is that such nurses did not want the patient to die under their care. They stated that if the patient died it would haunt them. This meant unnecessarily keeping the patient alive and prolonging suffering which was regarded by the majority as not adding value to the patient at all. On the other hand, nurses expressed desperation when the doctor’s orders were not clear. Having to

continue some activities such as blood gas analysis and continuous monitoring despite of little hope for survival was frustrating.

The other challenge experienced by the nurses was about who to contact when they had to move from curative to palliative care. Even though they normally have at least two or three contact persons on the patient's chart, it sometimes became hard for them to decide who to call. In such cases, some nurses suggested that the family should appoint one family member to act as the family representative. This person should be the one to be contacted in all situations if need be and he should be the one to liaise with the rest of the family.

Of much significance from the focus groups also was end-of-life discussions and decision making. When asked whether they are involved in EOL discussion and decision making process, nurses reported that they are not. Rather, the doctors make decisions and thereafter, they come and ask them of their opinions. In addition, it was found that a few most experienced nurses shared their opinions concerning the decisions that had already been made. In most cases, nurses agreed with decisions made without arguing. This was because of the fact that doctors do not listen to them nor value their inputs.

Nevertheless, nurses mentioned that being a team, they would like to be involved in the discussion and decision making process. Involvement would ensure that they can also share their ideas concerning the goal of care considering that they are the ones with the patient and family much longer time than any other staff. Despite of this, a few nurses did not want to be involved because they are not God to determine someone's life span. They believed that miracles do happen and sometimes even if doctors say the patient may not survive, some do come up.

The other major theme that came up from the focus group discussions was support for patients. This form of support implied to all those activities that would ensure patient's comfort in the dying process. As religious and spiritual support has been associated with a peaceful death, this form of support was supported by all nurse participants. Whereas it was

supported by all, not all of them were willing to offer this support. Although some of them were comfortable praying for the patients having consulted the families, a few mentioned that it was not their duty. In most cases, it was preferred to either ask families to bring their own spiritual leaders, organize for those patients who did not have families or arrange for some support organizations such as HospiVision to come and offer spiritual care. Because it was not always easy to get hold of spiritual leaders for those patients who did not have any, nurses suggested that the hospital should organize a specialized person on standby to be conducted when need be.

Without neglecting and until nature takes its course, nurses reported that they do offer basic nursing care to patients at EOL just like any other patient with a chance of survival. Above all, nurses mentioned that it is their duty to assess and minimize suffering by keeping the patient pain free all the time. To achieve this, nurses said they administer analgesics and sedatives as prescribed or when needed despite its double effect that could result to respiratory depression. Where not available, patient advocacy for prescription of these medications as reported comes in.

Additionally, family presence and participation in direct patient care was regarded as the other form of patient support. Families' presence was considered as not only a way to ensure that the patient is not alone during the dying process but it also acted as a way of gradually preparing the families to the imminent lose and a source of satisfaction with EOL care. Although nurses did not encourage families to participate in direct care, they reported that they always allow them to participate if they raise their desire to take part. The reason as to why they did not often ask families to take part was because of the fear that families may make mistakes that could risk their job and the institution. On top of these, nurses' presence with the patient was also viewed as important to the patient. In spite of this, not all nurses were able to do so because of nurses' shortage and lack of time as they were expected to conduct other activities out of the patient's room.

Moreover, it was noted that the noise level in the ICU is higher. Lowering the noise level of especially from the staff would ensure a quite surrounding hence a source of comfort to the patient. Apart from this, the minority of the participants suggested the need for a private room for the dying patients, families and other patients' privacy. Those who were against patients being taken to a private room mentioned that it was because the family would feel that the patient is being deserted and disowned.

Support for families appeared as the other most significant finding. This type of support involves all the actions that could make the families feel better even if it is emotionally draining and difficult to lose a close relative. Given the fact that nurses are mostly busy, they raised a need to have specialized support persons such as a spiritual leader, social worker, psychologist or support organizations to assist in comforting and reassuring the families. Bearing in mind the peoples' cultural differences in the present society, it was mentioned that patients' and families' wishes including practices of rituals should be respected. Even though this was the case, these practices would not always be valued especially where it could result in negative effects to other patients or the hospital.

Furthermore, open visitation was advocated by all nurse participants. In terms of accompanying the family when the patient's death neared, a few nurses reported that they would ask the family if they would like them to stay in the room for support. Due to limited time, most of them said it was not possible to stay with the family in the room because they had other assignments to carry out. Nonetheless, they were willing to make them as comfortable as possible before leaving them in the room by offering them whatever they needed such as tea, chairs, shock mixture or water among others.

Through experience, nurses had noted that often families do not receive early preparation concerning the patient's prognosis. It only came as a shock at the end when they were told that the patient may never survive. The nurse participants suggested that the doctors should start informative meetings from the first day of patient's admission so as to prepare the family of what to expect. At the same time, it was reported that nurses do not attend while

such meetings are being conducted. The need to be present in the meeting was stressed as this could ensure that the nurse knows what is going on hence the ability to support the family in terms of clarifying information during the meeting or afterwards at the bedside.

Lastly, support for nurses emerged from the focus groups as the other major theme. From the findings, it is clear that nurses face a lot of challenges and difficulties while caring for patients at EOL and more so the families of such patients. Some of the challenges experienced as mentioned earlier included psychological and emotional distress, lack of strategies of dealing with families, insufficient knowledge and experience in EOL care including lack of support from the institution. To overcome these challenges, nurses mentioned that they also need to be cared for and supported in order to be able to holistically care for the patients and their families. In the list, nurses mentioned the importance of debriefing sessions, training, team work, shift changes and time to adjust in between a patient's death and a new admission as ways that could support and enable them to cope.

In **chapter 4** which refers to stage II of the study, the tentative best practice guidelines for intensive care nurses on EOL care were developed and presented. Evidence obtained in the conclusions from stage I (steps 1-4) were integrated and synthesised. This involved clustering of similar conclusions drawn from all sources of data to form a new picture by means of inductive reasoning. The integrated and synthesised conclusions provided facts to support the recommendations within the best practice guidelines. Thereafter, a category of the strength of evidence was provided against each recommendation.

The guidelines carry recommendations that focus on communication, different aspects of caring and negative factors impacting on EOL caring. Communication recommendations are intended to inform nursing practice, management and nursing education regarding how to effectively communicate as health care team as well as instituting communication strategies in dealing with the dying patients and their families. Caring recommendations are intended to inform nursing practice, management and nursing education on how to promote quality care for patients and families at EOL and more so, the care needed by nurses in order for them to

continue rendering holistic nursing care. These aspects of caring includes: basic physical care, emotional care, spiritual care, presencing, support, and respect. Finally, negative factors impacting on caring at EOL recommendations have been provided to inform nursing practice, management and nursing education on what need to be improved so as to ensure quality EOL care.

Chapter 5 refers to stage III of the study. In this chapter, the results of the verification of the best practice guidelines for intensive care nurses at EOL were presented. This process was intended to assess the quality of the best practice guidelines, refine and further develop the guidelines and ensure its content validity. In general, the best practice guidelines were rated of high quality and with modifications, they were recommended for use by the expert verifiers.

6.3 LIMITATIONS

The following limitations were identified:

- This research was conducted in adult intensive care units at three academic hospitals in one province and did not include the experiences of the families, patients and critical care nurses in private hospitals within the same province. Therefore, the results from this study can only be generalized to similar contexts in South Africa.
- Once the patient was pronounced to be at EOL, there were no chances of them surviving to share their experiences of EOL care in critical care. Due to this, critically ill patients who had a predicted mortality of above 50% and survived were included in the study although not at EOL. Even though their responses contributed to patients' preferences, their responses may not have been exactly the same as those of the patients receiving EOL care.
- The best practice guidelines developed for EOL care in the intensive care unit are still informal. They still need to be implemented and piloted before they can be regarded as formal practice guidelines.
- As this research was intended for degree purposes, the researcher who is the student developed these guidelines individually. This means that the input from specialist

team that may be important during the whole process of guideline development is lacking in this study.

- Even though during the interviews the researcher tried to ask the questions in as much as a simpler form for better understanding, the use of the English language could have limited the participants from fully expressing their experiences of EOL care as this might not have been the case if they were allowed to speak their first languages. The researcher is not familiar with the local languages in South Africa and the chosen language was the second or third language for all the participants.
- Even though doctors are an important part of the intensive care team with their role in EOL care clearly emerging from the guidelines, their views and preferences towards EOL care were not included in the study.

6.4 RECOMMENDATIONS

In light of the research findings and limitations, the following recommendations were formulated for management, nursing education, clinical practice and further research.

6.4.1 Recommendations for management

The following suggestions were made for management:

- Some of the foreseen potential resource implications of applying the recommendations will be a need for extra support persons in the ICUs/other team members and a need for continuous staff training/education/workshops on end of life care. Based on this, there is a need for the management to put this into consideration in their long term plans of resource allocation.
- Because new evidence accumulates rapidly, guidelines should be reassessed for validity every five years to avoid outdated guidelines. To ensure this, the management should choose appropriate personnel to take part in the process and allocate resources for this process.

6.4.2 Recommendations for nursing education

The following recommendations were made for nursing education:

- Intensive care nurses expressed lack of expertise and competency on how to ideally deal with EOL care hence the need to incorporate this during the training period at the nursing training institutions.
- Provision of workshops and continuous education should be utilized in the ICUs as this could help the staff to learn more about strategies of dealing with families, patients and their own situations when caring for patients at EOL.

6.4.3 Recommendations for clinical practice

The following recommendations were made for the clinical practice:

- Following implementation, consultation with relevant professional bodies should be conducted, following which, the guidelines should be introduced in as many ICUs as possible as this could help improve the patients' and families' quality of EOL care as well as assisting the nurses on how to render such a care in an effective manner.
- In order to ensure adherence to the recommendations in the clinical area after its implementation, a request is made to the unit managers to frequently remind the staff to routinely put the guidelines into practice. To enhance the chances of sustainability for change, the unit managers should receive education and training related to the guidelines. The copy of the guidelines should be made available to everybody on the notice boards and should be attached to the chart of each patient receiving EOL care.
- Senior and experienced intensive care nurses should support the junior and newly qualified nurses so that they are able to manage the patient's and family's state as well as coping with the whole caring process.
- There is a need to promote interaction or communication between the nurses and doctors in the ICU regarding EOL care through workshops as open channels of communication and interactions may lead to satisfaction in the carers' side and quality EOL care to the patients and families.
- The guidelines clearly indicate the role of the doctors and specifically that there should be more discussions between the members of the team relating consensus of EOL care for a specific patient. Therefore, there is a need to incorporate the doctors when implementing these clinical guidelines to ensure ownership and collaboration.

6.4.4 Recommendations for further research

Further research is recommended to investigate the following issues which arose from the study:

- Since the study was contextual, further investigation is required to determine if the best practice guidelines can be transferred to other contexts in South Africa.
- Before the implementation of the guidelines, a pilot testing need to be carried out so as to assess the impact of implementing the recommendations such as finding out what could be the facilitators or barriers to implementing these guidelines.
- A further guideline development should be conducted with an addition of experiences/preferences/views of EOL care from other health care providers involved in EOL care in the ICU such as the doctors as they form part of an important team in the intensive care units.
- An additional search terms such as death and dying are important and they should be used during future research.
- Although they were not receiving EOL care, an opportunity was missed to talk to critically ill patients directly about EOL care which is the main subject of this thesis. This is because as an emotional topic, it was thought that unfamiliar language and cultural differences that are new to the researcher could affect the expression of questions related to EOL care and could cause misunderstanding. Due to this, it is recommended that a study be conducted by someone who is familiar with the South African culture on questions such as “based on your experience can you imagine what it might have been to die in the ICU? If someone was dying in the ICU, what do you think would be important for them?”

6.5 CONCLUSION

“A journey of a thousand miles begins with a single step” (Lao Tzu). As I end these thousand miles, I must say that the journey has been rewarding. It has been rewarding in the sense that the main aim of developing best practice guidelines for EOL care for intensive care nurses in Gauteng province, South Africa has been attained. After undergoing an assessment, these guidelines were found to be of high quality and recommended for use.

Of importance in this study, the views and preferences of the patients, families and the nurses in this setting were elicited and used as a source of evidence in the guideline development. Their inputs enhance the validity of the guidelines which are South African specific as it incorporates the context for which it has been designed. If implemented and used, these guidelines could guide intensive care team and more so, promote quality EOL care to the patients and their families.

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APPENDIX A

Faculty of Health Sciences
Medical School, 7 York Road, Parktown, 2193
Fax: (011) 717-2119
Tel: (011) 717-2745

Reference: Ms Tania Van Leeve
E-mail: tania.vanleeve@wits.ac.za
04 August 2010
Person No: 0705936E
PAG

Ms LC Kisorio
Campus Lodge Residence
48 Dekorte Street
Braamfontein
Johannesburg
2001
South Africa

Dear Ms Kisorio

Doctor of Philosophy: Approval of Title

We have pleasure in advising that your proposal entitled "*Best practice guidelines on end-of-life care for South African intensive care nurse practitioners in public sector intensive care units in Gauteng*" has been approved. Please note that any amendments to this title have to be endorsed by the Faculty's higher degrees committee and formally approved.

Yours sincerely

Mrs Sandra Benn
Faculty Registrar
Faculty of Health Sciences

APPENDIX B

UNIVERSITY OF THE WITWATERSRAND, JOHANNESBURG
Division of the Deputy Registrar (Research)

HUMAN RESEARCH ETHICS COMMITTEE (MEDICAL)
R14/49 Ms Kisorio L Chepkoech

CLEARANCE CERTIFICATE	**M10525**
PROJECT	Best Practice Guidelines on End-of-Life Care for South African Intensive Care Nurse Practitioners in Public Sector Intensive Care Units in Gauteng
INVESTIGATORS	Ms Kisorio L Chepkoech.
DEPARTMENT	Department of Nursing Education
DATE CONSIDERED	28/05/2010
DECISION OF THE COMMITTEE*	Approved unconditionally

Unless otherwise specified this ethical clearance is valid for 5 years and may be renewed upon application.

DATE 07/07/2010 **CHAIRPERSON** .....
(Professor PE Cleaton-Jones)

*Guidelines for written 'informed consent' attached where applicable
cc: Supervisor : Dr G Langley

DECLARATION OF INVESTIGATOR(S)

To be completed in duplicate and **ONE COPY** returned to the Secretary at Room 10004, 10th Floor, Senate House, University.
I/We fully understand the conditions under which I am/we are authorized to carry out the abovementioned research and I/we guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee. **I agree to a completion of a yearly progress report.**

PLEASE QUOTE THE PROTOCOL NUMBER IN ALL ENQUIRIES...

APPENDIX C

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences Research Ethics Committee
Fakulteit Gesondheidswetenskappe Navorsingsetiekkomitee

DATE: 17/01/2012

NUMBER	209/2011
TITLE OF THE PROTOCOL	Best practice guidelines on end-of-life care for South African intensive care nurse practitioners in public sector intensive care units in Gauteng
PRINCIPAL INVESTIGATOR	Ms Leah Chepkoech Kisorio **Dept:** Nursing Department, Faculty of Health Sciences, University of the Witwatersrand, Johannesburg **Cell:** 0766813094 **E-Mail:** [illegible]
SUB INVESTIGATOR	Not Applicable
STUDY COORDINATOR	Not Applicable
SUPERVISOR	Dr Gayle Langley **E-Mail:** [illegible]
STUDY DEGREE	PhD
SPONSOR COMPANY	Not Applicable
MEETING DATE	23/11/2011

The Protocol and Informed Consent Questionnaire were approved on 23/11/2011 by a properly constituted meeting of the Ethics Committee subject to the following conditions:

1. The approval is valid for 2 years period [till the end of December 2013], and
2. The approval is conditional on the receipt of 6 monthly written Progress Reports, and
3. The approval is conditional on the research being conducted as stipulated by the details of the documents submitted to and approved by the Committee. In the event that a need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Members of the Research Ethics Committee

Prof M J Bester	(female BHSc (Chemistry and Biochemistry); BSc (Hons)(Biochemistry); MSc(Biochemistry); PhD (Medical Biochemistry)
Prof R Delport	(female)BA et Scien; B Curationis (Hons) (Intensive care Nursing); M Sc (Physiology); PhD (Medicine); M Ed Computer Assisted Education
Prof JA Ker	MBChB; MMed(Int); MD – Vice-Dean (ex officio)
Dr NK Likibi	MBB ChM – Representing Gauteng Department of Health) MPH
Dr MP Mathebula	(female)Deputy Chair; Steve Biko Academic Hospital; MBChB, PDMM, HM
Prof A Nienaber	(female) BA(Hons)(Wits); LLB; LLM; LLD(UP); PhD; Dipl.Datametrics(UNISA) – Legal advisor
Mrs MC Nzeku	(female) BSc(NUL); MSc(Biochem)(UCL, UK) – Community representative
Prof L M Ntlhe	MBChB (Natal) FCS (SA)
Snr Sr J Phatoli	(female) BCur(Hons); B'Tech (Oncology Nursing Science) – Nursing representative
Dr R Reynders	MBChB (Pret), FCPaed (CMSA) MRCPCH (Lon) Cert Med Onc (CMSA)
Dr T Rossouw	(female) MBChB (cum laude); M Phil (Applied Ethics) (cum laude), MPH (Biostatistics and Epidemiology (cum laude), D Phil

Dr L Schoeman	(female) B.Pharm, BA(Hons)(Psych), PhD – Chairperson: Subcommittee for students' research
Mr Y Sikweyiya	MPH; SARETI Fellowship in Research Ethics; SARETI ERCTP; BSc(Health Promotion)Postgraduate Dip (Health Promotion) – Community representative
Dr R Sommers	(female) MBChB; MMed(Int); MPharmMed – **Deputy Chairperson**
Prof TJP Swart	BChD, MSc (Odont), MChD (Oral Path), PGCHE – School of Dentistry representative
Prof C W van Staden	MBChB; MMed (Psych); MD; FCPsych; FTCL; UPLM - **Chairperson**



DR R SOMMERS; MBChB; MMed(Int); MPharmMed.
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

◆Tel:012-3541330 ◆Fax:012-3541367 / 0866515924 ◆E-Mail: manda@med.up.ac.za
◆Web: //www.healthethics-up.co.za ◆H W Snyman Bld (South) Level 2-34 ◆ Private Bag x 323, Arcadia, Pta, S.A., 0007

2012/01/17MS: dd 2012/01/17: C:\Documents and Settings\user\My Documents\Protokolle\Grade briewe\Letters 2011\209 2011.DOC

APPENDIX D

CONDITIONS OF APPROVAL OF RESEARCH CONDUCTED GAUTENG DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT (GDHSD)

For approval by Director: Policy, Planning and Research

HEALTH AND SOCIAL DEVELOPMENT (GDHSD)
POLICY, PLANNING AND RESEARCH (PPR)
Enquiries: Sue le Roux
Tel: +2711 355 3212
Fax: +2711 355 3675
Email: Sue.LeRoux@gauteng.gov.za

CONTACT DETAILS OF THE RESEARCHER	
Date	25 August 2010
Tel number	+27-11-469-5547 (Office), +27-83-208-6265 (mobile)
Email	Leah.Kisorio@students.wits.ac.za
Researcher /Principal investigator (PI)	Leah Kisorio
Supervisor	Dr Gayle Langley
Institution	Nursing Department of University of Witwatersrand
Research title	**Best practice guidelines on end-of-life care for South African intensive care nurse practitioners in public sector intensive care units in Gauteng**

ONLY FOR APPROVAL OF THE RESEARCH STUDY TO BE CONDUCTED BY KISORIO LEAH CHEPKOECH ENTITLED "BEST PRACTICE GUIDELINES ON END-OF-LIFE CARE FOR SOUTH AFRICAN INTENSIVE CARE NURSE PRACTITIONERS IN PUBLIC SECTOR INTENSIVE CARE UNITS IN GAUTENG"

Approval is hereby granted by the Gauteng Department of Health and Social Development for the above research project to be conducted. Approval is limited to compliance with the following terms and conditions:

1. All principles and South African regulations pertaining to ethics of research are observed and adhered to by all involved in the research project. Ethics approval is only acceptable if it has been provided by a South African research ethics committee which is accredited by the National Health Research Ethics Council (NHREC) of South Africa; this is regardless of whether ethics approval has been granted elsewhere.

   Of key importance for all researchers is that they abide by of all research ethics principles and practice relating to human subjects as contained in the Declaration of Helsinki (1964, amended in 1983) and the constitution of the Republic of South Africa in its entirety. Declaration of Helsinki upholds the following principles when conducting research, respect for:

   - Human dignity;
   - Autonomy;
   - Informed consent;
   - Vulnerable persons;
   - Confidentiality;
   - Lack of harm;
   - Maximum benefit;
   - and justice

2. The GDHSD is indemnified from any form of liability arising from or as a consequence of the process or outcomes of any research approved by HOD and conducted within the GDHSD domain;
3. Researchers commit to providing the GDHSD with periodic progress and a final report; short term projects are expected to submit progress reports on a more frequent basis and all reports must be submitted to the Director: Policy, Planning and Research of the GDHSD;
4. The Principal Investigator shall promptly inform the above mentioned office of changes of contact details or physical address of the researching individual, organisation or team;
5. The Principal Investigator shall inform the above office and make arrangements to discuss their findings with GDHSD prior to dissemination;
6. The Principal Investigator shall promptly inform the above mentioned office of any adverse situation which may be a health hazard to any of the participants;
7. The Principal Investigator shall request in writing authorization by the HOD via PPR for any intended changes of any form to the original and approved research proposal;
8. If for any reason the research is discontinued, the Principal Investigator must inform the above mentioned office of the reasons for such discontinuation;
9. A formal research report upon completion should be submitted to the Director: Policy, Planning and Research of the GDHSD with recommendations and implications for GDHSD, the Directorate will make this report available for the HOD.

AGREEMENT BETWEEN THE GAUTENG DEPARTMENT OF HEALTH AND SOCIAL DEVELOPMENT (GDHSD) AND THE RESEARCHER

Ms. S le Roux

Director: Policy, Planning and Research

Date: 30/08/2010

Signature:

Name and surname of Principal Researcher

KISORIO LEAH

Research/Academic Institution

UNIVERSITY OF THE WITWATERSRAND

Date: 7TH SEPTEMBER, 2010

Signature:

ONLY FOR APPROVAL OF THE RESEARCH STUDY TO BE CONDUCTED BY KISORIO LEAH CHEPKOECH ENTITLED "BEST PRACTICE GUIDELINES ON END-OF-LIFE CARE FOR SOUTH AFRICAN INTENSIVE CARE NURSE PRACTITIONERS IN PUBLIC SECTOR INTENSIVE CARE UNITS IN GAUTENG"

APPENDIX E

Private Bag X39, Johannesburg 2000, South Africa
Tel: +27 (0) 11 488 4911, Fax: +27 (0) 11 643 1612
www.johannesburghospital.org

Gauteng Department of Health

Office of the CEO
Enquiries: M. Motjelele
(011): 488-3793
(011) 488-3753
26 August 2010

Sr. Leah Kisorio
Department of Nursing
University of the Witwatersrand

Dear Sr. Kisorio

RE: "Best practice guidelines on End of life care for South African Intensive Care Nurse Practitioners in Public Sector Intensive Care Units in Gauteng"

Permission is granted for you to conduct the above research as described in your request provided:

1. Charlotte Maxeke Johannesburg Academic hospital will not in anyway incur or inherit costs as a result of the said study.
2. Your study shall not disrupt services at the study sites.
3. Strict confidentiality shall be observed at all times.
4. Informed consent shall be solicited from patients participating in your study.

Please liaise with the Head of Department and Unit Manager or Sister in Charge to agree on the dates and time that would suit all parties.

Kindly forward this office with the results of your study on completion of the research.

Yours sincerely

Dr. Barney Selebano
Chief Executive Officer

APPENDIX F

MEDICAL ADVISORY COMMITTEE

CHRIS HANI BARAGWANATH HOSPITAL

PERMISSION TO CONDUCT RESEARCH

Date: 25 October 2010

TITLE OF PROJECT:

Best practice guidelines on end-of-life care for South African intensive care nurse practitioners in public sector intensive care units in Gauteng

UNIVERSITY: Witwatersrand

Principal Investigator: Kisorio Chepkoech

Department: Nursing Education

Supervisor (If relevant):.Dr Gayle Langley

Permission Head Department (where research conducted): Not that is apparent

Date of start of proposed study: 2010

Date of completion of data collection: 2011

The Medical Advisory Committee recommends/ ~~does not recommend~~ that the said research be conducted at Chris Hani Baragwanath Hospital. The CEO /management of Chris Hani Baragwanath Hospital is accordingly informed and subject to:-

- Permission having been granted by the Committee for Research on Human Subjects of the University of the Witwatersrand.
- the Hospital will not incur extra costs as a result of the research being conducted on its patients within the hospital
- the MAC will be informed of any serious adverse events as soon as they occur
- permission is granted for the duration of the Ethics Committee approval.
- The Clinical and Nursing Heads of ICU grant permission.

.....

Recommended/~~Not Recommended~~

(On behalf of the MAC)

Date: 8 Sept 10

PROF JOHN PETTIFOR
MBBCh, FCP (S.A.)
CHIEF PAEDIATRICIAN

.....

Approved/~~Not Approved~~

Hospital Management

Date: 27 Oct 2010

APPENDIX G

DATA EXTRACTION FORM

Article	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**	**10**	**11**	**12**	**13**	**14**
Study title														
Author and Year of publication														
Country														
Study design														
Methods used														
Sample														
Study population														
Inclusion criteria														
Major findings														

APPENDIX H

QUALITY ASSESSMENT OF QUANTITATIVE STUDIES

(http://www.jbiconnect.org/connect/info/about/jbi_ebhc_approach.php)

Reviewer:

Author and Year of publication:

NO	Methodological item being assessed	Not stated	Not explicitly stated	Clearly stated
1.	Does it clarify what was studied?			
2.	Is it clear how the samples were obtained?			
3.	Are the aims clearly stated?			
4.	Is the design appropriate to the stated objectives?			
5.	Are the measurements valid and reliable?			
6.	Are the statistical methods adequately described?			
7.	Was the statistical significance assessed?			
8.	Is the meaning of the main findings clear?			
9.	Can results be generalized?			
10.	Do results compare with other reports?			
11.	Are all researchers' names and qualifications present?			
12.	Are researchers' contact details present?			

Include: (Yes) (No) (Undefined)

Reasons:

APPENDIX I

QUALITY ASSESSMENT OF QUALITATIVE STUDIES (Paterson, Thorne & Canam, et al., 2001).

Reviewer:
Author and Year of publication:

No.	Methodological item being assessed	Not stated	Not explicitly stated	Clearly stated
1	Aim Clearly Stated			
2	Description of Study Population			
3	Sampling Procedure described			
4	Description of Inclusion Criteria			
5	Appropriate Sample Size determined			
6	Description of Data Collection Procedure			
7	Data Analysis Methods Described			
8	Categories identified			
9	Analysis Supported By Illustration			
10	Statement About Consent			
11	Permission to Undertake the Study			
12	Discussion pertaining to all significant findings			
13	Indication of Future Research			
14	Conclusion provided			
15	Identification of Limitations			

Include: (Yes) (No) (Undefined)

Reasons:

APPENDIX J

FAMILY MEMBER INFORMATION LETTER

Dear Sir/Madam,

Hello, my name is Leah Kisorio. I am an ICU nurse and currently registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for the degree of Doctor of Philosophy (PhD). I am hoping to conduct a research project to develop best practice guidelines on comfort care in intensive care units for South African intensive care nurse practitioners and I would like to invite you to participate and kindly consent to my including you in the interview.

The purpose of the study is to develop guidelines on how better the ICU nurses can care for the patients in the ICU. Because you have the experience of having a loved person in ICU, your views and recommendations would be so valuable. So I am inviting you to participate in the interviews that I will conduct among the family members who had their loved one in the ICU to elicit the family members' views on comfort care in the ICU. You are free to share what you think should have been done while your loved one was in the ICU so as to improve the level of care provided for the critically ill patients. The interview will last approximately one hour. I hope the completed study will provide the best practice guidelines on comfort care that will help to improve the quality of nursing care in South African context.

Participation in the study is entirely voluntary. You may choose not to participate or withdraw from the study at any time without any penalty. Your anonymity will be ensured by using a false name instead of your real name. No personal information will be reported throughout the study so as to avoid your identification and to ensure your confidentiality. I appreciate that you will derive no direct benefit from participating in the study. However, I hope that the completed study will clarify the guidelines needed for quality care in the ICU. To ensure I am able to capture all the information, I would like to use a tape recorder with your explicit consent. All the tapes will be kept in a locked cupboard for two years until publication or up to six years if publication will not have been done, thereafter they will be destroyed. All the data will be kept safe under password protected computer.

The appropriate people and research ethics committees of the University of the Witwatersrand, Pretoria and Gauteng Department of Health have approved the study and its procedures.

Thank you for taking the time to read this information letter. Should you require any further information regarding the study or your rights, you are free to contact me on telephone number **0766813094** or Anisa Keshav (011-717-1234) Witwatersrand research office or Manda Smith (012-3541330) Pretoria research office. If you consent to participate in this study, please complete the attached consent form.

Yours faithfully,

Leah Kisorio

APPENDIX K

FAMILY MEMBER CONSENT FORM FOR INCLUSION IN THE STUDY

I give permission to be included in the study.

I have read with understanding the content of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent to my being included in the study.

_____ _____

Date Signature

_____ (Signature of witness)

APPENDIX L

FAMILY MEMBER CONSENT FORM FOR TAPE RECORDING

I give permission to be tape recorded during the interview.

I have been given the opportunity to ask questions I might have regarding the procedure and my consent to my being tape recorded in the interview process.

_____ _____

Date Signature

_____ (Signature of the witness)

APPENDIX M

FAMILY MEMBER'S INTERVIEW GUIDE

Thank you so much for offering to help me. I want to stress that I am grateful for your experience and expertise but the actual discussion on comfort care in the ICU does NOT apply to you personally or your family member.

The participants were asked the following question:

Would you please tell me about your experiences *towards the nursing care that you and your family member received while in the ICU?*

The following were used as probes:

Please describe your views with respect to the following issues:

How did you experience the care rendered to your loved one in the ICU?

What do you think about your involvement in caring for your loved one while in the ICU?

Would you have liked to be more involved or less involved in the care of your loved one?

What are your views regarding the beliefs, culture and religion of your loved one in ICU?

Tell me more about how your relationship was between you and the nursing staff.

Do you feel you were involved in all decisions regarding your family member?

What recommendations would you give so as to help improve nursing care for ICU patients?

APPENDIX N

ANALYZED FAMILY MEMBER'S TRANSCRIPT

Purity

INTERVIEW FAMILY NO. 10 (FEMALE: SISTER)

PATIENT'S AGE: 36 Years

GENDER: FEMALE (BLACK)

DIAGNOSIS: PNEUMONIA/ATELECTASIS/SEPSIS

DAYS IN ICU: 6 DAYS

DAY OF DECISION: DAY 4

Me: Thank you so much for accepting to meet me today and share the information about the care that you and your sister receive here in ICU. Would you please tell me about how you experience the care that you and your sister are receiving here in the ICU?

F10:Mmm, this is her fourth day yeah, (mm) the first day when I came in here, OK I didn't know where or which bed she was (mm) I found someone at the reception table and we tried to ask and I was just ignored (mm) so I just had to walk through and to find the patient on my own (mm) the second day, I came in OK the nurse that we found on duty she was, she was OK, (mm) and when I came yesterday it was fine and OK, today when I came in I found the curtains around her bed and because I didn't know what was going on I wanted to ask first before I could get in and see her and I wanted to ask someone that was passing bye and I said excuse me, and she just ignored me so I am like (lifts her hands as if to question)you know, (mm) but you have to understand that may be they are also working under pressure but they should also have time to attend us who come to visit our patients you know what I am saying? (mm)

Me: So when you say the one nurse you met was OK, what do mean?

F10: No, she was friendly, supportive; she (pauses) was willing to answer the questions that we asked OK, the others when we asked they wanted us to ask the doctor because they didn't want to divulge (mm) but yesterday we didn't manage to see the doctor but today we have seen the doctor and he has told us that (mentions her name) she is getting worse and her lungs are not functioning no matter the treatment and even after they changed the machine that is helping her to breath because the first two days they were using a different machine yesterday and today it is this other machine that makes noise (OK)

Me: Apart from what you have told me, how has communication between you and staff been?

1

F10: The lady I spoke to yesterday is the only person that have spoken to me nicely like I said and then on Tuesday, (mm) I spoke to the doctor and she was OK (mm) she tried to explain the situation (mm) and then she was taken away I think she went for the rounds (mm)

Me: About the information you needed to ask regarding your sister, did you have to ask the staff or did they come and explain to you even without asking?

F10: No, we were at my sister's bedside and they found us there and I think they were doing their rounds (mm) so this lady approached me and asked me if I know what (mentions her name) my sister is suffering from (mm) and I said not so sure and she said 1,2,3 (mm) so she explained to us (OK)

Me: In terms of visiting your sister, are you satisfied with it?

F10: Mm, well I didn't even know, I only found out now that visiting time is 7a.m to 6p.m because we have always come here from 2p.m to 4p.m like in any other wards, (OK) but I didn't know, I only saw it now written on the entrance so I think this is very flexible hours (OK)

Me: So with you having not been with her most of the time, how do you feel about it?

F10:Eish, you know (mm) in the state that she is in, we can only hope for the best because I cannot say it is easy and when the doctor say she has to fight so all we need is to have faith because we are not God to control things (mm)

Me: So how has her state affected you as a family?

F10: Mmm it is me, my mother, her daughter, my two daughters and her 2 weeks old daughter (mm) we are staying together, (mm) we try not to talk about it (mm) you know, but the thing is that all of us are praying for her even though we are so worried about the way things are at the moment and it is hard to believe that OK, things might end up that way but then eish, I cannot say that it has been easy since the time she delivered (mm) you know, she is HIV positive and she refused to take her ARVs when she was pregnant and her lungs have not been so good all the time so I think now after birth the lungs have got so worse to an extent the doctors are saying they are collapsing and she is not able to get enough oxygen (mm) and I used to tell her to take her ARVs and she completely refused so now you see she is going to die and leave her kids alone and she is putting all of us under stress (mm) and we can almost not move on just to know she is critically ill and her live may never change (mm)

Me: Is there anything that the ICU staff can do that can make you feel better at this time?

F10: Mmm, just to support us and try to encourage us yeah

Me: What exactly do you want them to do?

F10: I mean, even though the road seem to be hilly and we know this person is not gonna, anything is possible (mm) they must be there for us because it will make us feel cared for to know someone minds about us also not only about the patient, (mm) they must treat us like human beings rather than ignore us when we try to talk or ask things as this lessens the stress in us (mm) and even though it may not change the situation of the patient, (mm) it still brings hope in us and sense of importance (OK) than to find you grumpy because these people are forever grumpy, (is it?) you will never find them smiling but I understand that you can never be friendly to everyone that comes in and goes out (mm) because you see like a couple of people in a day and by the time the day ends you may be so tired and I tell you, you won't know if you are not in such a situation as we are, (mm) only the person in such a situation understands what it means (mm) I know people can be impossible or demanding sometimes (mm) but you must try and find that humanity in you, but I mean just pretend, pretend and smile back because we need that light in your face to make us strong (mm) and they must remember that they are not here just for the salary, (mm) you are here to do your work and help (yeah)

Me: You mentioned that you are all praying for her, how important do you think this is at this moment?

F10: Mmm, I am not the type of a person that prays a lot but my sister, (mm) she believes in prayers and she is one person that can pray for you until you become revived, (mm) so you know every time I come here, I always tell her you know, you have always prayed for people and people get revived so I think it is time for you to pray for yourself (mm) because they say she can hear and they even encouraged us to talk to her and we tell her that her baby is fine and growing and all that but I know it might be difficult (mm) to be in pain but at times you must pray (mm)so you see when each day passes on and you don't hear anything bad you say thank God (mm)

Me: Would you as family like to be involved in direct care of your loved one at this point in time?

F10: Yeah, to some extent, but it might be difficult for us (why?) because you will come and she has all these things attached to her, the machines, and you are scared to touch because you think mm what if I mess, what if I switch the machine off accidentally? (mm) but if I can do whatever under supervision, (mm) then it would be great because you get to be close and even if she dies, we will be at ease as family that we also did something to her and she was not totally left in the hands of; I will call it strangers (OK) I also know of other people who will want to come and take care of their loved ones and give them some things to drink like muti like I saw it happen in the ward where she was before she was brought to ICU because they think it will make the patient get better (mm) but us we don't believe in such things as a family (OK)

Me: About the decisions that were made regarding the care of your sister, do you think you were involved in all the decisions?

F10: Mmm, only the sister that was taking care of her yesterday (mm) she explained that they were trying this other machine and they are trying other medication otherwise with the doctors not being around and the sisters not divulging the information I can say we have not received quite enough information as to what is happening and we still have some question marks that I may want to ask the doctor today (mm) and you know the doctors tell me most things, things that I don't want to hear (like?) Like things may not be good, or she is fighting and sisters may try to protect some other things you know, (mm)

Me: Do you have any recommendations that you would like to make that can improve the care of patients and families in ICU in the future?

F10:OK, like I said, you won't know until the situation happens to you (mm) as much as you say, talk, try to change people, there is nothing that you can do to change them (mm) so it is totally up to someone who cares for these patients (mm) if you are here, you should know what you are here for (mm) so be ready to help everyone that comes your way and don't let any person suffer in anyway (OK)

Me: Do you have anything more you would like to say or ask before we finish this interview?

F10: Mm no, I think I have said it all

Me: OK, thank you so much for your time and information

APPENDIX O

2.0 SIMPLIFIED ACUTE PHYSIOLOGICAL SCORE (SAPS II)

	Variable / Scoring Guidelines	Findings	Points	Score
2.1	**Age in Years** *age in years at time of last birthday*	< 40 40 - 59 60 - 69 70 - 74 75 - 79 > = 80	0 7 12 15 16 18	
2.2	**Heart Rate in beats per minute** *use the highest or lowest heart rate in past 24 hours whichever gives the higher number of points*	< 40 40 - 69 70 - 119 120 - 159 > = 160	11 2 0 4 7	
2.3	**Systolic Blood Pressure in mmHg** *use the highest or lowest blood pressure in past 24 hours whichever gives the highest number of points*	< 70 70 - 99 100 - 199 > = 200	13 5 0 2	
2.4	**Body temperature** *use highest temperature*	< 39 C > = 39 C	0 3	
2.5	**If on ventilation or CPAP PaO2 / FiO2** *use only if on ventilation or CPAP using the lowest ratio*	< 100 100 - 199 > = 200	11 9 6	
2.6	**Urinary Output in L per 24 hours** *if time period less than 24 hours adjust urine output for period to 24 hours*	< 0.500 0.500 - 0.999 > = 1.000	11 4 0	
2.7	**Serum Urea mmol/L** *use the highest value*	< 10 10 - 29.9 > 30	0 6 10	
2.8	**WBC count in 1000 per uL** *use the highest or lowest WBC in past 24 hours whichever gives the higher number of points*	< 1.0 1.0 - 19.9 > = 20	12 0 3	
2.9	**Serum Potassium in mmol/L** *use the highest or lowest potassium in past 24 hours whichever gives the higher number of points*	< 3.0 3.0 - 4.9 > = 5.0	3 0 3	
2.10	**Serum Sodium in mmol/L** *use the highest or lowest sodium in past 24 hours whichever gives the higher number of points*	< 125 125 - 144 > = 145	5 0 1	
2.11	**Serum Bicarbonate in mmol/L** *use the lowest value*	< 15 15 - 19 > 20	6 3 0	
2.12	**Serum Bilirubin in umol/L** *use the highest value*	< 4.0 4.0 - 5.9 > = 6.0	0 4 9	
2.13	**Glasgow Coma Scale** *use the lowest value if patient sedated* *use the score before sedated*	< 6 6 - 8 9 - 10 11 - 13 14 - 15	26 13 7 5 0	
2.14	**Chronic Diseases** *HIV positive with AIDS defining opportunistic infection or tumor; malignant lymphoma Hodgkins disease leukemia or multiple myeloma; metastases demonstrated at surgery, radiographically or other suitable method*	none metastic carcinoma hematologic malignancy AIDS	0 9 10 17	
2.15	**Type of admission** *scheduled surgery if scheduled at least 24h prior to operation; unscheduled if operated on with less than 24h notice; medical if no surgery within 1 week of admission to ICU*	scheduled surgery medical unscheduled surgery	0 6 8	

SAPS II Score	

APPENDIX P

PATIENT'S INFORMATION LETTER

Dear Sir/Madam,

Hello, my name is Leah Kisorio. I am an ICU nurse and currently registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for the degree of Doctor of Philosophy (PhD). I am hoping to conduct a research project to develop best practice guidelines on comfort care for South African intensive care nurse practitioners and I would therefore like to invite you to consent to my including you in my sample of patients that have had the experience of being treated in an ICU.

The purpose of the study is to develop guidelines on how better the ICU nurses can care for the patients in the ICU. Please be reassured, you are well enough to have been discharged from ICU so the study is not about your care. The only reason that you will be asked to consent and give your recommendations is because you have recently had personal experience of being nursed in an ICU. Your experience makes you an 'expert' on ICU care. You are free to share what you think should have been done while you were in the ICU so as to improve the level of care provided for the critically ill patients. The interview will be conducted when you are stable enough after your discharge to the ward from ICU. This will last approximately one hour. I hope the completed study will provide the best practice guidelines on comfort care that will help to improve the quality of nursing care in our South African context.

Participation in the study is entirely voluntary. You may choose not to participate or withdraw from the study at any time, which will have no effect on the services that you may receive from this institution or the health care providers. This will not affect your treatment in anyway. Your anonymity will be ensured by using a false name instead of your real name. No personal information will be reported in the study so as to protect your identity and ensure your confidentiality. I appreciate that you will derive no direct benefit from participating in the study. However, I hope that the completed study will clarify the guidelines needed for quality care in the ICU. If you agree to participate, I would like to tape record the interview with your permission. All the tapes will be kept in a locked cupboard for two years until publication or up to six years if publication will not have been done, thereafter they will be destroyed. All the data will be kept safe under password protected computer.

The appropriate people and research ethics committees of the University of the Witwatersrand, Pretoria and Gauteng Department of Health have approved the study and its procedures.

Thank you for taking the time to read this information letter. Should you require any further information regarding the study or your rights as a study participant you are free to contact me on the following telephone number **0766813094** or Anisa Keshav (011-717-1234) Witwatersrand research office or Manda Smith (012-3541330) Pretoria research office. If you consent to participate in this study, please complete the attached consent form.

Yours faithfully, Leah Kisorio

APPENDIX Q

PATIENT'S CONSENT FORM FOR INCLUSION IN THE STUDY

I give permission to be included in the study.

I have read with understanding the content of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent to my being included in the study.

_____ _____

Date Signature

_____ (Signature of the witness)

APPENDIX R

PATIENT'S CONSENT FORM FOR TAPE RECORDING

I give permission to be tape recorded during the interview.

I have been given the opportunity to ask questions I might have regarding the procedure and my consent to my being tape recorded in the interview process.

_____ _____

Date Signature

_____ (Signature of the witness)

APPENDIX S

PATIENT'S INTERVIEW GUIDE

Thank you so much for offering to help me. I want to stress that I am grateful for your experience and expertise but the actual discussion on comfort care in ICU does not apply to you personally or your family member because you are now out of the ICU.

The participants were asked the following question:

What were your experiences of nursing care while you were in the ICU?

The following were used as probes:

Please describe your needs and views with respect to the following issues:

What were your experiences with nursing care in the ICU?

Please tell me more about your family member being involved during your care in ICU

Does your culture matter during the care in ICU? If so how?

Tell me about how communication between you and nurses in the ICU was

How were your comfort measures met by the ICU nurses?

Please tell me more about having a religious leader visiting to ICU

How and who would you like to make the decisions about your care in ICU?

What do you wish should have been done during your nursing care?

What do you recommend as the best way to offer care to ICU patients?

APPENDIX T

ANALYZED PATIENT'S TRANSCRIPT

NIKI

KISORIO LEAH

INTERVIEW PATIENT NO. 7

GENDER: FEMALE

RACE: BLACK

AGE: 58 YEARS

DAYS IN ICU: 6 DAYS

DIAGNOSIS: COPD/DM/PNEUMONIA/DVT (SAPS II SCORE=59; PREDICTED MORTALITY 66.1%)

Me: Would you please tell me what were your views and experiences towards nursing care while you were in ICU

P7: For the first time I was in ICU the care was OK, and for the second time (mm) it was nice but other nurses make noises in the ICU with their radios on phones (mm) and you are still in pain and they are playing music (mm) right at my room and they say you must relax you must relax this is ICU (mm) that I didn't like (mm) but all I wanted is just for them to make things right for me and I get out of the place (mm) you see (yeah) but if you are sick you are sick you can't just say that people must treat you alright (mm) you don't even have energy or power and sometimes you can't talk because you have the tube in the mouth and you look helpless (mm) and nurses are not the same (mm) others are good and others are not good (mm)

Me: If you say some nurses are good and others are not good, did you experience such a difference among nurses?

P7: yeah, the good ones uhm, there was one sister, and I was asking her her number so that I can talk to her and say thank you even when I get discharged because she said to me I will be on leave from tomorrow, (mm) I liked her because she treated me so well (mm) you know what (mm) she treated me like her mum or her mum in-law (mm) you see (mm) and she said you know what don't worry but really she was a nurse and a guide to me all the way so most of them were fine to me (OK) and if I was able to choose I would have said I want so and so to be with me because I like the way they treat me (OK) yeah, they would come to me and say are you alright? are you in pain? How do you feel? How did you sleep? Just like that (mm) and I could

1

respond by signs when I was not able to speak but we could talk afterwards when I was much better (mm)

Me: How did you feel when you had someone who treated you so well?

P7: No, great, great (mm) I was even happy (mm) and I was asking them so now, if it is like this (mm) what must I do? They say no it is the way it is and it is normal so if a person is sick, (mm) you must treat the person with respect (mm) because I am not here because I am coming to enjoy myself (mmmm) but I come because I want to be treated because I feel the pain and I can't even move my body (mm) you see (mm) but the two, that girl and a boy (mm) they treated me so well (mm) they were talking to me nicely, handling me nicely, encouraging me you see (yeah) hey they are very good those people they have courtesy and they can make you get well quickly because they treat you as if you belong to them (mm)

Me: You also mentioned about some nurses not being so good, what experiences did you encounter with them?

P7: No, others were rough (mm) others don't greet (mm) they just come and start working (pauses) open water and start to wipe you (mm) and after that they say OK hold that, I can't hold you have to pull yourself up and they say come, come, and when I vomit it makes them more gross (mm) like this other sister right, (mm) she wipes me (mm) and she wipes this side of my body and then she says I must turn and hold on the bed so that she can wipe the other side and I was not able to because I was feeling terrible pain and then she got gross (mm) but oh well there is nothing I can do because I am not pretending and this is not my home (mm) just like that (OK) sometimes they wrap you so hard and you feel much pain and even on the face when they put the oxygen the put it in, put it in (stresses the putting it in to mean it was done roughly) and they can scratch your face and I mean why can't they do it gently?

Me: Did you have anyone come to visit you in the ICU?

P7: Yes, they used to come and they looked so stressed when they saw me very sick and they look so terrified and stressed about my sickness and they were happy when the tubes were removed and when they saw me out of the ICU (mm) they could speak to me and I could hear them speaking and I could tell they were not feeling good about my sickness and the problem with the tubes you cannot speak (mm) and so I could not be able to answer them but I only saw

them shortly then they go home and I could feel bad when they go because I want them to stay longer (OK)

Me: You said you wanted your family to stay much longer when they come to visit, how important would this be to you while in ICU?

P7: yes, if the hospital can allow them to stay I am happy because if the time is short you feel bad and sometimes you wish they were closer to you to give you the warmth and you feel nice just to see somebody by your side even though the pain I was having this time round was too much, (mm) the pain was the problem and that pain I was going through I thought no, (mm) I won't make it (mm) but only because of God, (mm) I am out but really I was too sick this time (mm)

Me: How do you think about your family member being involved in your care?

P7: That is not a problem but is it not the job of a nurse?

Me: Yes it is, but given a choice, would you wish your family can do some other things in your care?

P7: No, it won't be alright, (mm) I am not happy about that because the nurses they know their jobs (mm) and they see every dirt that you are carrying with you so it is better if the nurses can do all the care (OK) and sometimes you haven't got family (mm) who is going to do that for you ? is it not the nurse)(yeah) and even if I have people, I would still want the nurse (OK)

Me: Tell me about your beliefs, culture and values; did it matter while in ICU?

P7: Mmm I believe in my ancestors, but the problem is I didn't put my ancestors in front (mm) I put God first the only one I was crying to was God,(mm) I said God can you please help me (mm) and it was when I tried to ask my ancestors (mm) that I see some things, do you know this? And then they showed me the people, I said ha ha and I got a funny shock and I said no, no, (mm) no, no,no, this is not what I want (mm) you see, I asked my granny (mm) and she said no this is not right (mm) and I said to them I want you to help and instead of helping me you are showing me a lot of bad things? I didn't like it because they were calling me to go to them and this was disturbing my mind too much (mm) too much, others are killings and I didn't like other part and I said let me put God first and have hope in him for him to help and heal me (OK) and even my pastor and family used to pray for me and I believe in prayers because it gives me

power (OK) and without prayers I feel useless (OK) and some people are very strong in faith and performing miracles and they can help you in lots of things (mm)

Me: In terms of information, do you think you received enough information regarding your condition and treatment?

P7: Yeah, the doctors did tell me and I understand whatever they did and what is going on in my life (OK)

Me: What about the nurses, did they give you any information?

P7: No the problem is I was just asking the doctors and I did not ask nurses because I was thinking it is not their job (OK)

Me: How comfortable were you in the ICU?

P7: Mmm the pain was too much (mm) and the problem is when you are in pain they say we just gave you medicine (mm) but I think the pain was a lot and the other thing is it was too much noise like I said otherwise nothing much (OK)

Me: In terms of decision making, was your family involved in decision making towards your care?

P7: Uhm I am not sure if they were involved (OK)

Me: Given a choice, would you have liked them to be involved in the decision making process towards your care?

P7: Mmm, other private hospitals I have been to, do so, (OK) but it could be nice if they involve them because they can help you when you are very sick but they must be careful because other families are very difficult to deal with and they can disturb the doctors (OK)

Me: Do you have any recommendations you would like to make that can improve nursing care of the future patients and families?

P7: Mmm the care was good apart from the few nurses (mm) but I must say they must pray for patients to give them power and to be courteous to their patients (OK) that is all

Me: OK, thank so much for your time and information

APPENDIX U

INTENSIVE CARE NURSES' INFORMATION LETTER

Dear Colleague,

Hello, my name is Leah Kisorio. I am an ICU nurse and currently registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for the degree of Doctor of Philosophy (PhD). I am hoping to conduct a research project to develop best practice guidelines on end-of-life (comfort) care for South African intensive care nurse practitioners.

I would like to invite you to be part of the focus group discussion which will aim at eliciting the nurses' views and understanding on comfort care in the ICU. The focus group discussion will last approximately one hour. The group will consist of eight nurses and each of you will be given an opportunity to share your views on the topic of discussion. With your permission, the discussion will be tape recorded to ensure that all the information is recorded for transcription.

Participation in the focus group discussion will be entirely voluntary. You are allowed to withdraw from the study at any time if you wish so without any penalty. While confidentiality and anonymity may be desirable, it cannot be guaranteed during focus group discussion. However, to ensure your confidentiality I undertake to ensure that all information will be kept confidential and safe from unauthorised access once it has been collected. To ensure your anonymity, no identification of your personal information will be given in reporting on your opinions. If you consent to be part of the expert group, please complete the attached consent forms and return it to me in the addressed and stamped envelope enclosed. All the tape recorded information will be only available to me as the researcher. All the tapes will be kept in a locked cupboard for two years until publication or up to six years if publication will not have been done, thereafter they will be destroyed. All the data will be kept safe under password protected computer. Results of the study will be given to you on your request.

I appreciate that you will not derive any benefit from participation in this study. However, I hope that the results of the study will help clarify the guidelines needed for quality comfort care in the ICU. The appropriate people and research ethics committees of the University of the Witwatersrand, Pretoria and Gauteng Department of Health have approved the study and its procedures.

Thank you for taking the time to read this information letter. Should you require any further information regarding the study or your rights as a study participant you are free to contact me on the following telephone number **0766813094** or email me using the following address: *ljkisorio@yahoo.co.uk*, or Anisa Keshav (011-717-1234) Witwatersrand research office or Manda Smith (012-3541330) Pretoria research office.

Yours faithfully

Leah Kisorio

APPENDIX V

INTENSIVE CARE NURSES' CONSENT FORM FOR INCLUSION IN THE STUDY

I give permission to be included in the study.

I have read with understanding the content of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent to my being included in the study.

_____ _____

Date Signature

_____ (Signature of the witness)

APPENDIX W

INTENSIVE CARE NURSES' CONSENT FORM FOR TAPE RECORDING

I give permission to be tape recorded during the focus group discussion.

I have been given the opportunity to ask questions I might have regarding the procedure and my consent to my being tape recorded in the focus group discussion process.

_____ _____

Date Signature

_____ (Signature of the witness)

APPENDIX X

INTENSIVE CARE NURSES' FOCUS GROUP DISCUSSION GUIDE

Introduction: Experience in caring for critically ill patients make you 'experts' in intensive care.

1. Today we are here to talk about end-of-life (comfort) care in ICU. What comes to your mind when you think about caring for a patient in end-of-life?

Probes:

a. I am sure you have an experience of patients dying in ICU, is it difficult or easy?

b. How do you experience this process? (Stories of caring for patients and family elicited)

2. Do you think that guidelines could have helped you care for the patient or family better?

3. What would you recommend as absolutely imperative to ensure good end-of-life care?

Probes:

a. Can you elaborate?

b. What about the family, what would be essential to ensure good family care?

4. What do you think the patients themselves would recommend?

5. What do you think the families would recommend?

6. How do you feel about their wishes?

7. What would be very helpful even if not imperative to assist you to render comfort care?

8. What would you need to support care for you at this difficult time?

9. Would you like to add anything more?

Thank you so much for sharing your expertise and experiences.

APPENDIX Y

A PORTION OF TRANSCRIBED/ANALYZED FOCUS GROUP INTERVIEW WITH INTENSIVE CARE NURSES: GROUP 2 INTERVIEW

KEY:

RESEARCHER (R)

INTERVIEWEE (NUMBERS 1-7)

R: Today we are here to discuss about end-of-life care in ICU. What comes to your mind when you think about caring for a patient who is 'not for escalation of treatment' or 'not for resuscitation' or for 'palliative management'?

4: To me I think it is a challenge between the doctors and nurses and the family (mm) in a way that you know, you are like you are challenged mentally, spiritually (mm) and you ask yourself how am I going to reassure this family of the patient (mm) that now there is no hope (mm) especially if the patient doesn't do well because it is the process of your understanding of the family (mm) you expect this family to understand something that they have never experienced before (mm) and it challenges your communication skills (mm) because you need that therapeutic communication and skill so that you can be able to share or allow the family to share their concerns (yeah)

6: We have built that relationship and then we get this news, so it is so depressing and it is challenging (mm)

2: I agree with all sisters, like say you have built your relationship with families (mm) when the doctors proclaim that he or she is not doing well (mm) their faith (family) is being challenged and you as the nurse, because most us are Christians or believers (mm) we have to build these familys' faith even stronger because we have seen the situations where doctors have given the report that this is the situation but God changes everything and we have seen people getting better from that perspective (mm) so it is a real challenge

7: I think this process could be made easier if we are all being taken a long (mm) relatives, staff members, you see if we come to accept the progress of the patient that, that is where we are going (mm) that we are not winning, everybody is being taken along that we have reached the end and everybody is in agreement with the situation (mm) I think it becomes easier, so everybody accepts that there is nothing that could be done (mm)

5: The most stressing and challenging thing is when you implement that, because you have to go through looking at hemodynamics and you know seeing the patient going down until the end (mm) it drains you and thereafter, you are expected to admit another patient and just carry on as if nothing has happened because that bed is going to be utilized by another patient, and thereafter, there is no debriefing, there is nothing expected, you carry on (mm)

R: The way everyone has spoken, it looks like it is really a very difficult process (All agree some by yes, and some nod heads) what is it that you think could be done that can be of support while undergoing this caring process?

5: Yeah at least after the patient has died, someone to come and talk to you (mm) because we are human beings (mm) probably you will have these emotions, (mm) you know for a healthy nurse to be able to take care (mm), she or he will also need to be cared for so that he or she cares for other people effectively (mm) you remember you practice holistic care (mm) emotionally, spiritually, physically (mm), you also have all those aspects in you (mm) so post the patient has

died (mm) someone should come to you and say this has happened, so how do you feel? (mm) in future, how can we deal with this? (OK)

2: I think err before the patient demises, they can be gasping even for two days (mm) and for the unit manager, it would be OK if a nurse changes from one patient to another because if yesterday you looked after this patient and you are so emotionally drained (mm) let somebody take over and nurse the patient and see how they cope (mm) and even during the day or whenever, she should just come a long and ask how are you doing because other people we are so weak emotionally (mm) we just break down and if you are not coping with that type of patient they should change you to another patient (mm)

4: I think it also important as colleagues to assess the emotions and feelings of other colleagues (mm) for instance you have just come back from bereavement and they allocate you this other patient who is at the end of life (mm) and the patient has been in the ward for some time (mm) and everybody else had a chance and you are fresh, it is your first day (mm) and delegation is there, you must (mm) so such things we need to consider them (mm) because you might not cope (mm) so it is not only management because they are not there, they don't see us (mm) (*All agree by mm/nod heads*) it is us in this situation (mm) but we strain so let us support each other (mm)

1:It is very important to take care of one another (mm) because really it can remind you of what has just recently happened (mm) I think it is a good thing to consider such issues you know (mm) which patient to allocate to somebody in that state (OK)

R: Once decision has been made for palliative management to begin, as a nurse, what is very important to ensure comfort for such a patient?

1: I think pain management is very important and also spiritual you know (mm) if possible invite the pastor to come and pray for the patient and allow the family to have time with their beloved one (mm)

2: I think total nursing care should continue till the end (mm) we turn them, we feed them, we do everything that you do to a person who has a potential to live (mm)

4:With my experience, (mm) most of the patients especially the end of life (mm) they prefer the family members (mm) even though they don't say anything (mm) but they prefer the love, the support of the family members and they expect the family members to give them the care that they know, even if the family members are not trained (mm) they are not doctors (mm) but they are looking at them with those eyes that they feel safe, they feel secured (mm) so we encourage the family members to come even at odd times (*All agree by mm*) even though we tell them that when we do our routine they must please excuse us (mm) but in between just come and hold hands (OK) we need somebody to be at peace (mm)

5: To ensure comfort we still bath patient, we make them lie on the bed that is dry and then we make them to be pain free

R: Sometimes when analgesia was not prescribed and you assess the patient and you find he or she is in pain, is there any step you can take as a nurse to ensure comfort?

5: Patient advocacy comes in (mm) you talk to the doctor (*All agree mm/nod heads*) you are the one in contact with the patient for a longer time (mm) so you inform the doctor that this is what I see (mm) can you kindly prescribe something to manage pain (mm)

TRANSCRIBED FOCUS GROUP 2. (PORTION).

GROUP 1 C.T. - -

EXPERIENCES OF EOLC	SUPPORT FOR PATIENTS	SUPPORT FOR FAMILIES	SUPPORT FOR NURSES
I find it to be very depressing	ensure comfort	allow the family to have time with their	after the patient has died
it is a challenge	we still bath patient,	beloved one	someone to come and talk to you
a very depressing situation	total nursing care should continue till the end	allow them to sit by the patient's bedside	communication need to be carried forward
challenged mentally, spiritually	noise level needs to be down	doctor speaks to them	
you are so emotionally drained	pain relief	need to be told from day one about the prognosis,	a nurse changes from one patient to another
it challenges your communication skills	we turn them, we feed them, environment,	just to prepare them	take care of one another
		involve relatives	support each other as colleagues
there is no hope	we organize somebody to come and pray	it won't be a shock	
you are with the family		social worker to talk to the family	just come back from bereavement
you don't know what to tell them	pray together	you also being there to be able to explain anything	consider them
	they prefer the family members		you might not cope
you carry onthere is no debriefing,		if they want to pray they can pray	need to be cared for
you have built your relationship that is the most difficult,	encourage the family members to come even at odd times	others want to do their last respect may need privacy	we don't have that substantial experience
	hold hands		junior nurses should be given information
division between the families dilemma	somebody to be at peace	need a shoulder to lean on	
NO, I don't want this to happen to me	Patient advocacy	hug, give a chair, tea	
it was very difficult, terminating the treatment	you are in contact with the patient longer	wanted to participate, respect their views	
still now it haunts me	talk to the doctor	observe and you explain	
who to call in such situations			
most close person to the patient			

GROUP 2

GROUP 3

APPENDIX Z

COMMON THEMES FROM THE FOUR SOURCES: STEPS 1-4 OF STAGE I

Theme	Systematic review	patients	Families	Nurses
Clear Communication	Y	Y	Y	Y
Confusion/inconsistent information	Y		Y	Y
Information/progress report/preparation	Y	Y	Y	Y
Have questions answered/someone available	Y		Y	Y
Comfort/pain/hygiene	Y	Y	Y	Y
Hope for recovery		Y	Y	Y
Little hope/futile care (Aggressive interventions)	Y			Y
Hospitality	Y	Y	Y	Y
Trust the care/team	Y	Y		
Compassion	Y	Y	Y	Y
Nurses presence for patient/family during death/time/shortage/dignity	Y	Y	Y	Y
Involvement in decision making (told/not involved)	Y	Y	Y	Y
Involvement in direct patient care	Y	Y	Y	Y
Open access/Family presence	Y	Y	Y	Y
Religious/Spiritual support (Known/unknown)	Y	Y	Y	Y
Reassurance	Y	Y	Y	Y
Respect of privacy (room/information)	Y	Y		Y
Respect wishes/involve families in decisions	Y		Y	Y
Respect culture/rituals/traditions		Y	Y	Y
Noise		Y	Y	Y
Anxiety		Y	Y	
Emotional/psychological stress in caring process	Y	Y	Y	Y
Difficulty dealing with families/communication challenges	Y			Y
Difficulty transitioning to palliative care/prolonging patient suffering	Y			Y
Consensus/agreement to palliative care/discord	Y		Y	Y
Advocacy	Y		Y	Y
Support person				Y
Debriefing/support	Y			Y
Team work/cooperation	Y			Y
Nurses' training/Knowledge/competence	Y	Y		Y
Shift changes				Y
Time to adjust				Y
Continuity in nursing care	Y			
Frustration with physicians (dissatisfaction)	Y			Y
Lack of support in EOLC	Y			Y

Key: Y represents yes

APPENDIX AA

AGREE II INSTRUMENT

DOMAIN I. SCOPE AND PURPOSE

1. The overall objectives of the guidelines is (are) specifically described:

1 Strongly disagree	2	3	4	5	6	7 Strongly agree

Comments

2. The health question (s) covered by the guidelines is (are) specifically described

1 Strongly disagree	2	3	4	5	6	7 Strongly agree

Comments

3. The population (patients, public etc) to who the guidelines is meant to apply is specifically described

1 Strongly disagree	2	3	4	5	6	7 Strongly agree

Comments

DOMAIN 2: STAKEHOLDER INVOLVEMENT

4. The guidelines development group includes individuals from all the relevant professional groups

1 Strongly disagree	2	3	4	5	6	7 Strongly agree

Comments

5. The views and preferences of the target population (patients, public, etc) have been sought

1 Strongly disagree	2	3	4	5	6	7 Strongly agree

Comments

6. The target users of the guidelines are clearly defined

1 Strongly disagree	2	3	4	5	6	7 Strongly agree

Comments

DOMAIN 3: RIGOUR OF DEVELOPMENT

7. Systematic methods were used to search the evidence						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

8. The criteria for selecting the evidence are clearly described						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

9. The strengths and limitations of the body of evidence are clearly described.						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

10. The methods for formulating the recommendations are clearly described						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

11. The health benefits, side effects, and risks have been considered in formulating the recommendations.						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

12. There is an explicit link between the recommendations and the supporting activities						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

13. The overall guidelines have been externally reviewed by experts prior to publishing						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

14. A procedures for updating the guidelines is provided						
1	2	3	4	5	6	7

Strongly disagree						Strongly agree
Comments						

DOMAIN 4: CLARITY OF PRESENTATION

15. The recommendations are specific and unambiguous						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

16. The different options for management of the conditions or health status are clearly described						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

17. Key recommendations are easily identifiable.						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

DOMAIN 5: APPLICABILITY

18. The guideline describes facilitators and barriers to its application						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

19. The guideline provides advice matters and/or tools on how the recommendations can be put into practice						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

20. The potential resource implications of applying the recommendations have been considered.						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

21. The guideline presents monitoring and/or auditing criteria.						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

DOMAIN 6: EDITORIAL INDEPENDENCE

22. The views of the funding body have not influenced the content of the guideline						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

23. Competing interests of guidelines development group members have been recorded and addressed.						
1 Strongly disagree	2	3	4	5	6	7 Strongly agree
Comments						

OVERALL GUIDELINES ASSESSMENT

For each question, please choose the response which best characterizes the guideline assessed:

1.Rate the overall quality of this guideline						
1 Lowest possible quality	2	3	4	5	6	7 Highest possible quality
Comments						

2. I would recommend the guidelines for use

Yes	
Yes, with modifications	
No	

NOTES

APPENDIX AB

PANEL OF EXPERTS INFORMATION LETTER

Dear Sir/Madam,

Hallo, my name is Leah Kisorio. I am an ICU nurse and currently registered as a student at the University of the Witwatersrand, in the Department of Nursing Education for the degree of Doctor of Philosophy (PhD). I am hoping to conduct a research project to develop best practice guidelines (BPG) on end-of-life (comfort) care for South African intensive care nurse practitioners.

I would be very grateful if you would accept this invitation to be part of an expert group in assisting me to verify the developed BPG. If you agree to participate you will be required to review these BPG using the AGREE II instrument so as to assess the accuracy and quality of the BPG. An AGREE II instrument users guide will be attached to the AGREE II instrument and sent to you. This overall assessment will be used to make a judgement of quality of the BPG.

Participation in the verification process is entirely voluntary. You may choose to withdraw from the study at any given time without penalty. I undertake to ensure that all information will be kept confidential and safe from unauthorised access to ensure your confidentiality. No identification of your personal information will be given in reporting on your opinions so as to ensure your anonymity. If you consent to be part of the expert group, please complete the attached consent form, verify the BPG and return both your consent form and assessment recorded on the AGREE II instrument to me in the addressed and stamped envelope enclosed.

I appreciate that you will not derive any benefit from participation in this study. However, I hope that the results of the study will help clarify the guidelines needed for quality care in the ICU. The appropriate people and research ethics committees of the University of the Witwatersrand, Pretoria and Gauteng Department of Health have approved the study and its procedures.

Thank you for taking the time to read this information letter. Should you require any further information regarding the study or your rights as a study participant you are free to contact me on the following telephone number **0766813094** or email me using the following address: *ljkisorio@yahoo.co.uk* or contact Anisa Keshav (011-717-1234) Witwatersrand research office or Manda Smith (012-3541330) Pretoria research office.

Yours faithfully

Leah Kisorio

Date_____

APPENDIX AC

PANEL OF EXPERTS' CONSENT FORM

I give permission to be included in the study.

I have read with understanding the content of the information sheet and I have been given the opportunity to ask questions I might have regarding the procedure and my consent to my being included in the study.

_____ _____

Date Signature

_____ (Signature of the witness)